

Thinking
about me?

Essential psychological care for
people with learning disabilities

enter ▶



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Contents

Acknowledgements..... 8
 Learning outcomes for the resource..... 8

Unit 1. Introduction

Learning outcomes..... 10
 Why do we need this resource? 10
 Who is the resource for?12
 How should I use the resource?13
 How long will it take to complete?.....14
 Recommendations to managers14
 Features of the resource.....15
 Case studies.....16

Unit 2. Setting the scene: learning disability and society

Section 1. Definitions and context of learning disability.....20
 Learning outcomes..... 20
 Definitions of learning disability 20
 How should I tell someone he or she has a learning disability?22
 Consequences of diagnosis.....23
Section 2. Different people, different times.....24
 Learning outcomes.....24
 Society and learning disability24
 Long-stay hospitals and the move to community living.....25
 A better life for everyone..... 27
 Stigma, social comparison and social support: effects on
 psychological well-being28
 Psychological resilience33
Section 3. Capacity 34
 Learning Outcomes 34
 Capacity to consent..... 34

MORE ▶

Contents

Unit 3. Living with a learning disability

Learning outcomes.....	38
Section 1. Communication.....	38
Learning outcomes.....	38
Communication.....	38
Social communication disorders.....	41
Section 2. Transitions.....	43
Learning outcomes.....	43
Leaving school	43
Relationships and sexuality.....	45
Section 3. Carers	47
Learning outcomes.....	47
Carers' roles	47
Family carers.....	47
Paid carers.....	49

Section 4. Sexual abuse.....	51
Learning outcomes.....	51
Sexual abuse and its effects	51
Psychological interventions for abuse	52
Section 5. Bereavement and loss	53
Learning outcomes.....	53
Normal and complicated grief	53
Expressions of grief in people with learning disabilities	54
Coping with the death of another person.....	54
Supporting clients to cope with bereavement.....	57

MORE ▶

Contents

Unit 4. Psychological support for people with learning disabilities

Section 1. Prevalence and assessment of psychological difficulties in people with learning disabilities59

- Learning outcomes.....59
- Prevalence of psychological difficulties in people with learning disabilities59
- Diagnostic overshadowing.....61
- Screening and assessment of mental health needs61
- Screening measures.....62
- Personality.....65

Section 2. Making sense of it all: using psychological theories and formulation.....66

- Learning outcomes..... 66
- What is psychological formulation? 66
- Frameworks for formulation: the 5 Ps model 68
- An example of formulation 69
- Using formulation when working with teams..... 71
- Sharing a formulation with a person with a learning disability 72

Section 3. Psychological therapies for people with learning disabilities..... 72

- Learning outcomes..... 73
- Psychological interventions for people with learning disabilities: past history and current views 73
- Who can be a therapist? 74
- The stepped-care model 74
- Developing a therapeutic relationship 75
- Why am I seeing you anyway? Clients' understanding of psychological therapy..... 76
- Psychological therapies 80
- Cognitive therapies.....81
- Necessary skills for cognitive therapy.....82
- Psychodynamic psychotherapy83
- Positive Behaviour Support83
- Behavioural Family Therapy 84
- Art Therapy and Music Therapy..... 84
- Adapting psychological therapies for people with learning disabilities85

MORE ▶

Contents

Unit 5. Physical health and psychological well-being

Section 1. Psychological effects of physical health on people with learning disabilities89

- Learning outcomes.....89
- Physical health’s role in the psychological well-being of people with learning disabilities89
- Physical activity and psychological well-being.....89
- Weight management90
- Adherence to medication/medical intervention90

Section 2. Neurological and genetic conditions and psychological well-being91

- Learning outcomes.....91
- Epilepsy91
- Non-epileptic seizures92
- Dementia.....93
- Genetic syndromes.....96

Section 3. Palliative care98

- Learning outcomes.....98
- End-of-life issues for people with learning disabilities.....98
- Promoting choice in end-of-life care98
- Preparing people with learning disabilities for death99

You’ve completed the resource..... 101



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- Particular thanks go to the members of staff from Key Community Supports and representatives from the Tenants Advisory Group.

Learning outcomes for the resource

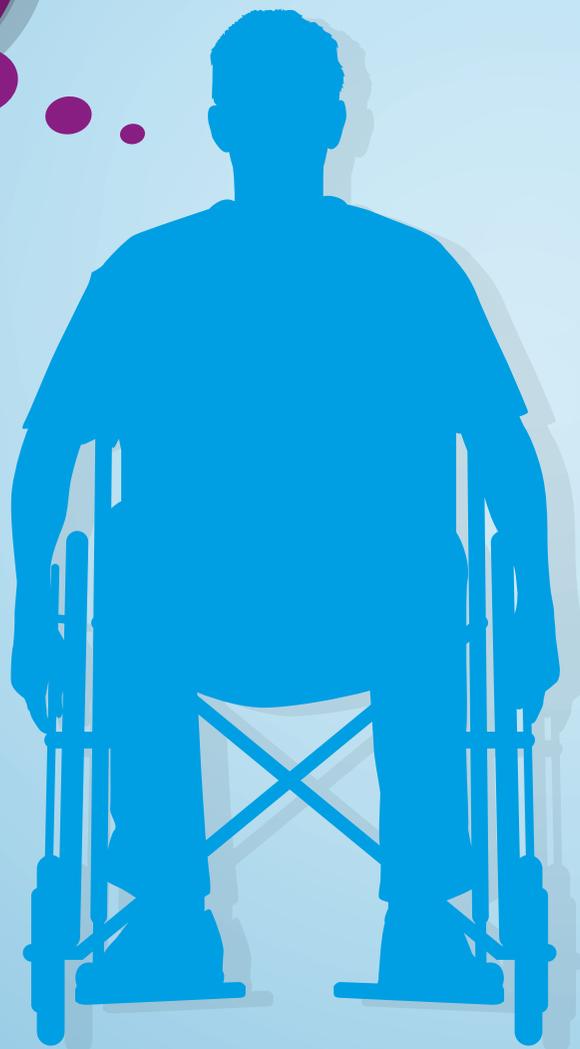
On completion of the resource, you will be able to:

- identify the role psychological factors play in the lives of people with learning disabilities
- describe fundamental psychological theories and models, particularly those relevant to learning disabilities and mental health.





me...

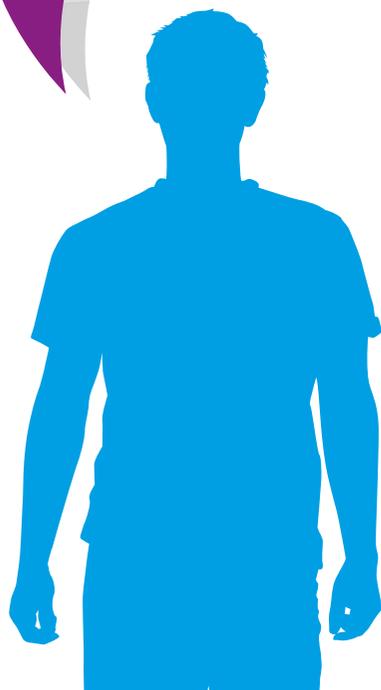


Unit 1

Introduction

Unit 1. Introduction

“ I felt better when someone listened to what I was talking about. Helped me to talk about issues from my past that had been bothering me. Helped me to sort out my head. I don't feel as angry as I did. I am a lot better and happier. ”



Christopher

Learning outcomes

By completing this unit, you will:

- understand the purpose and structure of the resource
- decide how you will complete your study.

Why do we need this resource?

People with learning disabilities lead varied lives and often do not experience psychological difficulties. But for professionals working with people with learning disabilities, an appreciation of an individual's life from a psychological perspective can increase understanding and responsiveness to any difficulties the person may present. This resource therefore aims to develop healthcare practitioners' existing knowledge and understanding of psychological care.

Changes to pre-registration nursing qualifications and initiatives such as Strengthening the Commitment [Box 1.1] have highlighted the need for staff to have psychological awareness. The value of psychological therapies is also recognised through initiatives such as The Matrix [Box 1.1]. For people with learning disabilities, developments over recent decades have meant that psychological therapies are now more accessible and effective.

Unit 1. Introduction

Box 1.1. Strengthening the Commitment and The Matrix

Strengthening the Commitment, the report of the UK Modernising Learning Disabilities Nursing Review, aims to ensure that people with learning disabilities of all ages have access to expert learning disabilities nurses and that their families and carers get the best support and care. It also seeks to make best use of learning disabilities nurses throughout the entire health and social care system and improve the career image of learning disabilities nursing as a whole. You can access the report at:

→ <http://www.scotland.gov.uk/Publications/2012/04/6465>

The Matrix is a joint Scottish Government/NHS Education for Scotland (NES) document that aims to provide NHS Boards with information on:

- strategic planning for psychological therapies
- governance of delivery of these therapies
- a summary of empirically validated psychological therapies.

It is aimed at supporting clinicians and service managers to focus on the timely delivery of evidence-based psychological therapies for service users, including those with learning disabilities. You can access it at:

→ <http://www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/matrix.aspx>

NES has commissioned this resource to support staff to deliver the best possible care for people with learning disabilities. Its intention is to help you understand psychological factors that may affect anyone (with or without a learning disability), but some of which, such as stigma, may be particularly relevant to people with learning disabilities.

The resource covers:

- definitions of learning disability
- communication abilities
- life histories, such as living in long-stay hospitals
- family and personal relationships
- experiencing stigma and discrimination
- physical health difficulties
- bereavement
- psychological therapies for people with learning disabilities.

We expect that sections of the resource will be more relevant to some learners than others, depending on job roles and levels of experience. The resource doesn't aim to provide all the information on each topic – we'll signpost you to further reading you can explore – and it isn't a manual that will teach you how to deliver psychological therapies, if you don't already do so. Instead, we hope to raise your awareness of these therapies, although this may lead to you considering options for training in a particular therapy.

Unit 1. Introduction

Who is the resource for?

Thinking About Me? is for all health professionals who work with people with learning disabilities. It will be particularly useful for registered nursing staff, but is also relevant for other members of health teams and front-line social care and third sector staff.

Thinking About Me? can be used in a number of ways:

- **team leaders and clinical managers** can use it to support continuing professional development (CPD) or teaching and development work with staff members
- **front-line staff** can use it as part of induction or CPD activity.

Here are some things that learners have told us after completing the resource.

“ Although I was aware of much of the material, the resource helped me to consider some of the people I work with in a more psychological way. I have also been able to use sections of the resource to help student nurses who complete placements with me to gain an understanding of issues that may affect people with learning disabilities. I am now interested in finding out more about psychological therapies and how they could be used with people with learning disabilities.”

Charge nurse, community

“ I completed my nursing qualification last year and am now working in an in-patient unit. We had some teaching on psychological issues within my course, but the resource has been a really good way of finding out more about why some of the patients we see might present with certain behaviours. The section on formulation was a particularly good way to understand a person's difficulties and I have started to use this approach when working as a keyworker for patients in my ward.”

Staff nurse, in-patient unit

Unit 1. Introduction

“ I had never really thought about working psychologically with clients, but after completing the resource I have started to realise that a lot of the work we do, such as Essential Lifestyle Planning, is psychological. The resource helped me to be more aware of the risk that we don't think enough about people's histories. Although we try to avoid it, there is often a high staff turnover in some of our care packages. I now wonder whether some of the behaviours that clients present with are because of the other losses they have experienced in the past. I will be encouraging our staff to think more about psychological issues when we have meetings to talk about clients who are presenting with behaviours that challenge our service.”

Care provider, service manager

How should I use the resource?

We want you to use this resource in the way that best suits you, your team and your organisation. The activities that appear throughout will play a key part in helping you further develop the knowledge, skills and attitudes that are central to your role.

You can use the resource for individual learning, learning as a group or team, in a facilitated learning event, or as a mixture of all these approaches. Whichever you favour, we recommend that you seek some opportunities for group discussions to help you to understand your individual experiences within a broader context and enhance your learning. There are many questions that are best answered – and points that are best discussed and expanded upon – with colleagues.

We would encourage you to keep a learning log in which you can accumulate copies of your learning activities and examples from practice that provide evidence of your learning. The log should also help you to reflect on the knowledge and understanding you've gained and identify your future learning needs around the topics covered.

Unit 1. Introduction

How long will it take to complete?

There is no set time-limit for completing the resource. Some people may choose to work through individual units gradually, while others might wish to use it more intensively. The resource is intended to be used and referred to regardless of the current stage of your career.

In general, we estimate that the whole resource will require around 22 hours of study. The estimated hours of study, including discussion times with a peer and/or mentor, for each unit are:



Recommendations to managers

Ideally, we would suggest that this resource be undertaken by two or more people within the organisation (or across organisations) to provide peer support. We would also recommend the involvement of a mentor, someone with a background in delivering psychological therapies to people with learning disabilities. He or she can help participants to think about their learning from the resource and how they can apply this in their daily work.



Unit 1. Introduction

Features of the resource

There are several features that you'll see throughout the resource.



Learning outcomes

These tell you what you are expected to know by the end of each unit or section.



Further reading

Useful reading sources and links to further information are highlighted to allow you to explore particular topics in greater depth.



Key psychological concepts

These are theories or models that can help you to better understand the psychological basis for particular issues for people with learning disabilities.



Video stories

The resource provides video links to interviews with people with learning disabilities talking about their lives and how issues raised in the resource affect them. They are intended to help you think about how these issues might affect real people.



Learning activities

The activities will help you to think about and understand topics within a unit. You may be asked to do some further reading or find out information about your local learning disability service. Learning activities are often related to a case study. You should answer the questions in each activity and then discuss your responses with your peer and/or mentor.



Something to think about

These are not learning activities, but interesting points you may want to consider in your own practice or perhaps find out more about through further reading or discussions with colleagues or clients.

Unit 1. Introduction

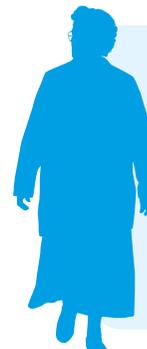
Case studies

We make use of the case studies described below throughout the resource. Life events and their potential psychological effects are illustrated. The case studies do not depict real people, but the issues they face reflect those that many people with learning disabilities may experience in everyday life. You should consider your own experiences of working with, or knowing, people with learning disabilities when working through the resource.

Four people feature in the case studies



Robert is a 22-year-old man with a mild learning disability. He attended mainstream school but received learning support throughout his education. He has not had any further education or employment since leaving school at the age of 18. Robert lives with his parents and sister, Jane, who is 18.



Christina is a 64-year-old woman who has a moderate learning disability. Christina was admitted to a long-stay hospital at the age of 30 when her mother died and her father was unable to cope with working and caring for Christina. She moved into her own tenancy six years ago and receives daily support from an independent care provider. Christina has a sister in England who telephones her weekly.



Michael is a 32-year-old man with a profound learning disability and cerebral palsy. He lives with his parents, who provide most of his care. Michael has epileptic seizures that have proved difficult to control. He continues to have seizures at night-time, meaning that his parents must monitor his well-being overnight. He attends a local day centre three days a week.



Patricia is a 28-year-old woman with a moderate learning disability. She lives with her parents and siblings in a household that can often be chaotic. She has been excluded from a number of activities due to conflicts with various people. At the moment, she is spending most of her time at home.

Unit 1. Introduction



Learning activity 1.1

Consider the following with your mentor.

- Do Robert, Christina, Michael and Patricia sound like people you have worked with?
- Have you had any training in psychological theories or therapies?
- If you have, what have you learnt?
- Do you use psychological theories or therapies in your everyday work?
- If you have, how have you used these?
- Write down what you would hope to gain from this resource.



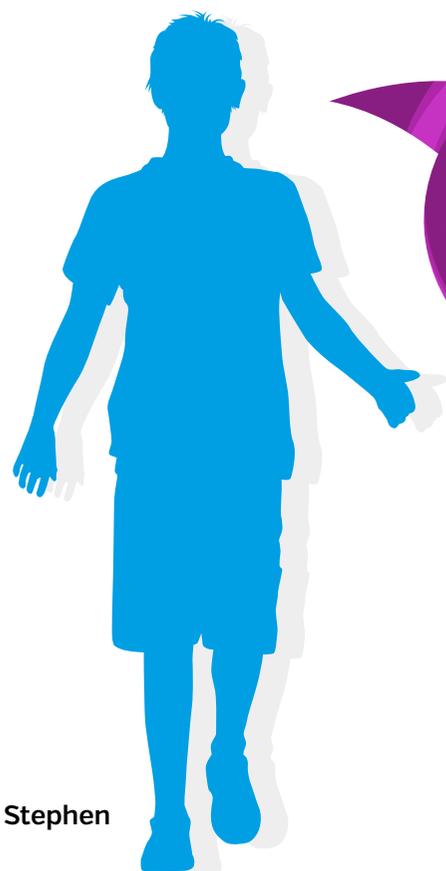
Unit 2

Setting the scene:

learning disability

and society

Unit 2. Setting the scene: learning disability and society



Stephen

“ The nurse asked me questions about how I got on at school and what I could do in the house. The psychologist got me to do a lot of puzzles, a lot of tests. Then we had a meeting with my Mum and Dad as well. They said I have a learning disability. They said I could find it difficult to do some things. But I know that. I know that I can't read or write. ”

Consistent understanding among professionals about what a learning disability is and how it is diagnosed is essential. But professionals should always be aware of the psychological effects, either positive or negative, that diagnosis may have on a person.

A label like “learning disability” may make society view the person in a different way, sometimes leading to stigma and discrimination. This unit covers these issues, including a look at some historical aspects of society's attitudes toward people with learning disabilities. Maintaining an awareness of this history is important when working with clients for whom the psychological effects remain relevant to this day.

Unit 2. Setting the scene: learning disability and society

Section 1.

Definitions and context of learning disability



Learning outcomes

By completing this section, you will:

- be able to define learning disability
- be aware of differing terminologies used
- describe how learning disability is assessed
- highlight potential difficulties in the assessment process.

Definitions of learning disability

We assume that if you're using this resource, you'll have some experience of working with people with learning disabilities and have an understanding of what a learning disability is. "Learning disability" is the term the Scottish Government uses in its policy and practice documents and we will follow that convention.

There are nevertheless many terms in everyday use that describe learning disability. These include **developmental disability**, **intellectual disability** or **learning difficulty**, as well as out-of-date terms that are no longer seen as acceptable, such as mental handicap, mental deficiency, mental subnormality and mental retardation. Using these terms interchangeably can cause confusion for people with learning disabilities, families and professionals, and some can cause distress.

People with learning disabilities vary, but everyone with a learning disability will be considered to have a significant lifelong condition that:

- affected their development (before the age of 18)
- means they need help to understand information, learn skills and cope independently (IQ < 70 and impairments in 'everyday' functional skills)

Learning disability is often described in terms of an intelligence quotient (IQ) of less than 70:

- **mild** learning disability relates to an IQ of 50–69
- **moderate** to IQ 35–49
- **severe** to IQ 20–34
- **profound** to IQ of less than 20.

Standardised assessment of adaptive functioning can be more difficult than assessment of IQ, so there was a tendency in the past to focus on intellectual functioning on the assumption that deficits in adaptive and social functioning would be present to an equivalent degree. It's important to remember that this is not always the case.

Unit 2. Setting the scene: learning disability and society



Video Story



This video clip shows people who have been labelled as having a learning disability discussing the term and what they think about it.



Something to think about ...

A person with a learning disability cannot be sentenced to the death penalty in some North American jurisdictions. This has led to a number of appeals against the death penalty and has provoked debate about the nature of assessment for learning disability. Assessment of learning disability can, in some cases, literally be a life-and-death matter.

You may wish to read the information at:

→ <http://www.deathpenaltyinfo.org/category/categories/issues/mental-retardation>

and consider ethical issues around the use of the term “learning disability”.



Further reading

- Schalock, R.L., Luckasson, R.A. & Shogren, K.A. et al [2007]. The renaming of mental retardation: understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities*, 45, 116–124.
- Williams, T., McKenzie, K. & McKenzie, A. [2009]. Training care staff about the concept of learning disability. *Learning Disability Practice*, 12, 34–37.

Unit 2. Setting the scene: learning disability and society



Learning activity 2.1

Go to the following web link:

→ <http://www.deathpenaltyinfo.org/documents/renamingMRIDDApril2007.pdf>

where you will be able to read a full version of the Schalock et al. paper.

- Write down the different terms for learning disability they describe and define what they mean in different countries.
- What, in your view, would be the best term, and why?

How should I tell someone he or she has a learning disability?

We refer here to people receiving their diagnosis in adulthood.

Everyone will vary in the way they respond to a diagnosis of learning disability. The diagnosis will not be a surprise for many, particularly if they had received additional support at school. Others will not be expecting, and will not wish, such a diagnosis. The reactions of parents or other relatives can also influence a person's response.

Before diagnostic assessment, you should ensure that the person:

- knows the purpose of the assessment before granting consent (see the "Capacity to consent" section later in this unit for discussion of issues around consent)
- understands the consequences of being given (or not being given) a diagnosis of a learning disability
- understands what a learning disability is – as we suggested earlier, there is often confusion about different terms, such as "learning difficulties" and "learning disabilities", and easy-read materials with clear explanations might be helpful.

After diagnostic assessment, you should:

- ask the person how he or she feel about the diagnosis
- ask what difference he or she thinks the diagnosis will make to his or her life
- try to address concerns that the person, relatives or carers have about being given (or not being given) a diagnosis of a learning disability.

Unit 2. Setting the scene: learning disability and society



Learning activity 2.2

Case study: Robert

Robert has struggled to obtain work since leaving school four years ago. He attended mainstream school and received learning support, but was never formally diagnosed with a learning disability. The occupational psychologist and job coach at the Job Centre nevertheless have suggested that he may have a learning disability.

Robert's mother and father attend their GP with Robert. The GP refers Robert to the local adult learning disability service and requests an assessment. Robert is subsequently diagnosed with a mild learning disability.

- What emotions might Robert experience following this diagnosis?
- What advantages to Robert could you foresee as a result of this diagnosis?
- What disadvantages to Robert could you foresee as a result of this diagnosis?

Consequences of diagnosis

The diagnosis, or label, of learning disability can have significant practical consequences for people. It can affect whether someone is eligible for specialist services and benefits or is subjected to something such as detention in hospital. It can also affect people's chances of gaining employment or accessing further education.

In addition to the practical effects of diagnosis, the psychological effects can also be significant. For some, it may come as a relief that there is a "name" for their difficulties, while others may feel that the diagnosis will make them "different" from others and stop them from, for instance, getting a job or starting a relationship. Having a diagnosed learning disability can have a profound effect on a person's view of him or herself.

General society's attitudes can also have a substantial effect on how someone feels about having a certain condition. People with learning disabilities are among the most excluded groups in society, experiencing **stigma** and **prejudice**. The development during the 20th century of long-stay hospitals in which people were isolated from the community may have exacerbated this. We look at this in more detail in the next section.



Something to think about ...

Fiona Pilkington killed herself and her daughter, Francesca, after sustained bullying from groups of youths in their area. It is believed that Francesca was targeted because of her learning disability. You can read more about this tragic case at the following weblink:

→ <http://www.theguardian.com/uk/2009/sep/17/mother-daughter-fire-killed>

Unit 2. Setting the scene: learning disability and society

Section 2.

Different people, different times



Learning outcomes

By completing this section, you will:

- reflect on how society's views of learning disability have changed over recent decades
- examine and discuss the factors and approaches that supported and encouraged the move toward community integration
- identify and report issues of stigma for people with learning disabilities.

Society and learning disability

In the early part of the 20th century, people with learning disabilities were often viewed as presenting a “danger” to society because of the perceived risk of offending behaviour or having children who would also have disabilities [Box 2.1]. This view was characteristic of the “eugenics” movement [Box 2.2] and was instrumental in promoting the development of long-stay hospitals.

Box 2.1. The Radnor Report, 1908

The following text from a report published in 1908 by the “Royal Commission on the Care and Control of the Feeble-Minded”, known as the Radnor Report, exemplifies the thinking about learning disability that prevailed at the time.

Investigations compel the conclusion that there are numbers of mentally defective persons whose training is neglected, over whom no sufficient control is exercised, and whose wayward and irresponsible lives are productive of crime and misery ... and of much continuous expenditure wasteful to the community and to individual families ... feble-mindedness is largely inherited ... consequently there are strong grounds for placing mental defectives of each sex in institutions where they will be retained and kept under effectual supervision as long as may be necessary ... to make procreation impossible.

[Quoted by Ryan & Thomas, 1980]

Unit 2. Setting the scene: learning disability and society

Box 2.2. The eugenics movement

Francis Galton, a psychologist, suggested in the early 1900s that society would gradually deteriorate because of “dysgenic” procreation among people with learning disabilities. Galton believed that a scheme of “marks” for family merit (taking into account factors such as occupation) should be given and early marriage between families of high rank be encouraged through monetary incentives. This, Galton stated, would encourage “eugenic” marriages and, subsequently, children with more favourable genes.

Although the eugenics movement was discredited, with scientists arguing against and rejecting the simplistic theories of inheritance proposed by eugeneists, programmes that included (in some cases) forced sterilisation continued into the 1970s, particularly in Scandinavian countries. Sterilisation was often carried out not for medical reasons or due to risks to the individual, but because of concerns that people with learning disabilities might produce children.



Further reading

- Dikotter, F. [1998]. Race culture: recent perspectives on the history of eugenics. *The American Historical Review*, 103, 467–478.
- Ryan, I. & Thomas, F. [1980]. *The Politics of Mental Handicap*. London: Penguin.

Long-stay hospitals and the move to community living

Institutions such as Lennox Castle Hospital in Stirlingshire and Gogarburn Hospital in Midlothian were opened in the early 20th century. Part of their rationale was to ensure that people with learning disabilities, or others who were considered “immoral” in character (such as unmarried mothers), were kept away from the general population and therefore could not produce children. It was also argued, however, that these institutions served a therapeutic role and afforded some protection for vulnerable people.

Typically, these institutions were “self-contained”, with work, recreation and medical facilities provided within. Men and women were segregated in wards and people were allowed few personal possessions: in some cases, clothing was provided by central stores. At its peak in the 1970s, 1700 men and women lived in Lennox Castle Hospital.

Once admitted to the hospital, residents often found it difficult to be discharged, particularly if contact with family members had reduced over time. The process of being admitted was rarely one in which the person had a choice, leading to psychological distress for the person and, in many cases, their families.



Something to think about ...

Listen to former residents talking about their time living in Lennox Castle Hospital:

- ➔ <http://www.youtube.com/watch?v=sglyodTUoTA>
- ➔ <http://www.youtube.com/watch?v=8N6oC6Ge7vw&feature=youtu.be>

Unit 2. Setting the scene: learning disability and society

The move away from such institutions took root in many countries in the latter half of the 20th century. Several enquiries into long-stay hospitals (such as the Ely and South Ockendon Hospital reports) highlighted significant concerns regarding the quality of care and, in some cases, institutionalised abuse of patients. This led to efforts to reform long-stay hospitals, or even to move away from this model of care entirely. Alongside these developments, **normalisation** and, later, **social role valorisation** philosophies began to influence the development of services that were integrated within the wider community. Wolfensberger, a leading authority on the subject, described normalization as:

... utilization of means which are as culturally normative as possible, in order to establish, enable or support behaviours, appearances, experiences and interpretations which are as culturally normative as possible.

He described social role valorisation as:

The most explicit and highest goal of normalization ... the creation, support, and defence of valued social roles for people who are at risk of devaluation.

O'Brien & Tyne [1981] articulated these philosophies in the **five accomplishments**: community presence, choice, respect, competence and community participation.

Government institutional care for people with learning disabilities ceased with the hospital closure programme of the 1990s. There are now no long-stay hospitals, although a number of private or charitable organisations have developed smaller residential units that generally aim to provide care and treatment for people with specific difficulties in addition to their learning disability. Many middle-aged or older people with learning disabilities will nevertheless have lived in long-stay hospitals. The possibility of enduring psychological effects of this model of care should always be considered when working with these people.



Further reading

- Department of Health and Social Security. [1969]. Allegations of Ill-treatment of Patients and Other Irregularities at the Ely Hospital, Cardiff: Report. London: HMSO.
- Department of Health and Social Security. [1974]. Report of the Committee of Enquiry into South Ockendon Hospital. London: HMSO.
- O'Brien, J. & Tyne, A. [1981] The Principle of Normalisation: a foundation for effective services. London: Campaign for the Mentally Handicapped.

The Scottish Executive and England and Wales NHS/social services documents **The Same as You?** and **Valuing People** set out plans for providing appropriate residential and day support for people with learning disabilities. These can be accessed the following weblinks.

- **The Same as You?** <http://www.scotland.gov.uk/Resource/Doc/1095/0001661.pdf>.
- **Valuing People** https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

A discussion of the transition needs of someone moving from long-stay to community placement can be found at:

- <http://www.nursingtimes.net/moving-from-a-long-stay-hospital-to-the-community/206349.article>

Unit 2. Setting the scene: learning disability and society



Learning activity 2.3a

Case study: Christina

Christina is a 64-year-old woman who has a moderate learning disability. She was the only child still living with her parents when her mother died [her three elder sisters had left home by that point]. Christina was always seen as being “slow” at school. She was admitted to a long-stay hospital at the age of 30, following her mother’s death.

- Reflect on what Christina’s feelings might have been when she was admitted.
- How might these have affected her behaviour at the time?
- How might that experience continue to affect her in later life?
- Christina’s father was told that it would be better for him not to visit her after she was admitted. How might that have affected him and his family?
- What long-term effects do you think living in an institution might have on Christina?
- How might these be reflected in her behaviours?



Learning activity 2.3b

Christina moved into her own tenancy six years ago and receives daily support from an independent care provider. She has contact with one of her sisters, Margaret, who lives in England but telephones weekly.

- **“Community care is a good thing.” Reflect on this statement and write down what might be the benefits of the move to community care for someone like Christina. Also note any disadvantages you can think of.**

A better life for everyone

The vast majority of people with learning disabilities live in communities. The exact models of care vary depending on local authorities’ interpretation of government policies. Some areas will offer only individual tenancies, while others may provide a mix of shared tenancies and core-and-cluster accommodation. The emphasis of most models of care is now on supported choice and independence.

Unit 2. Setting the scene: learning disability and society



Learning activity 2.4

- Identify what models of care are offered in the area in which you work. Establish why these models are used. You may need to search for social work information to help you with this activity.
- What effects (positive and negative) on psychological well-being do you think these models have?

Stigma, social comparison and social support: effects on psychological well-being

Stigma

Although the move away from long-stay institutions was a positive change that removed the overt segregation of many people with learning disabilities, the **stigma** of a learning disability can remain. This can be explicit, such as name-calling, or more subtle, like someone avoiding developing a friendly relationship with a near neighbour who has a learning disability.



Key psychological concept

Stigma

Stigma is a process by which certain groups, such as those with mental illness or learning disability, are **marginalized and devalued** by society because of values, characteristics or practices that differ from the dominant cultural group. Stigma occurs through a combination of stereotyping, prejudice and discrimination in the presence of an imbalance of power among different groups.

Stigma can affect the person (when they may think of themselves as having the same characteristics as the stereotype) or those around the person, such as family or professionals. It is known as “courtesy” stigma when applied to professionals and “affiliate” with family members.

Research has shown that stigma can result in:

- withdrawal from others
- low self-esteem
- depression
- anxiety
- lack of opportunities for future development, either because the person does not attempt them, or because other people do not offer the person the opportunity
- differential treatment by organisations – criminal cases may not proceed because of a view that a person with a learning disability could not be a reliable witness, for instance.

Unit 2. Setting the scene: learning disability and society

Some people with learning disabilities may try to avoid stigma by concealing details of the school they attended, avoiding making friends with other people with learning disabilities and minimising their difficulties. Others might not actually identify with having a disability and may give concrete examples of being restricted from activities, such as not being able to read or drive a car. Family members, friends or professionals can attempt to “protect” the person by avoiding the use of labels such as “learning disability” or even denying that the person has a learning disability.

Another psychological process, called **social comparison**, may also affect how a person feels about him or herself. We will look at this in the next section.



Further reading

- Jahoda, A. & Markova, I. [2004]. Coping with social stigma: people with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48, 719–729.
- Todd, S. & Shearn, J. [1997]. Family dilemmas and secrets: Parents' disclosure of information to their adult offspring with learning disabilities. *Disability and Society*, 12, 341–366.



Video Story



This video clip shows a group of people discussing their views and experiences relating to stigma and bullying and thinking about positive ways to tackle these issues.

Unit 2. Setting the scene: learning disability and society



Learning activity 2.5

Case study: Robert

Robert was diagnosed with a mild learning disability by his local adult learning disability service. He still does not have a job or any other structured activity.

Robert will sometimes go into town. He occasionally goes to the bookmakers when he has some money and to a local pub. A group of young men, one of whom was at school with Robert, also go to the bookmakers. Robert often hears the young men laughing and whispering and thinks they might be talking about him. The manager of the bookmakers is aware of the problems between Robert and the group, but decides not to intervene.

The young men sometimes say they will help Robert. They take his money and place bets for him, sometimes on horses Robert has expressly said he doesn't want to back. Sometimes when Robert's horse has lost, the young men laugh and say things like "Tough luck Robert, a loser always backs a loser". On one such occasion, Robert starts to shout at the group and attempts to push one of them.

The manager comes into the front of the shop, where the group say they can't understand the change in Robert's behaviour and that they always try to be nice to him. Robert tries to tell the manager what happened and the fact that he feels picked on and mocked by the group but he doesn't really know how to say this.

The manager bars Robert from the bookmakers.

Consider what you've learned about stigma and answer the following questions.

- **Does the behaviour of the group of men and the manager reflect stigmatisation in society? List the reasons why or why not.**
- **How else might the manager have dealt with this situation?**

Unit 2. Setting the scene: learning disability and society

Social comparison

The way in which stigma affects an individual is not necessarily straightforward. In addition to stigma, the psychological process of **social comparison** can either protect or intensify the effects of stigma on a person's psychological well-being.



Key psychological concept

Social comparison

Social comparison theory explains the processes by which a person evaluates him or herself compared to others. Social comparison is considered an active process: the person actively chooses with whom to compare him or herself.

It is suggested that making comparisons that present a person positively (such as comparing with someone less able) may be adaptive, with positive implications for psychological well-being. On the other hand, repeatedly making comparisons with others who are more able may adversely affect psychological well-being.

Research with people with learning disabilities has found that many will compare themselves positively on some aspects of themselves against peers who do not have learning disabilities. This is called a **lateral** comparison and may protect self-esteem. It has also been found that many people with learning disabilities will see others with learning disabilities as less capable and fortunate, in many ways, than they are. This is called a **downward** comparison and may again protect self-esteem and psychological well-being.

As you can see, the relationship between stigma and psychological well-being is not always straightforward.



Further reading

- Paterson, L., McKenzie, K. & Lindsay, W. [2012]. Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 25, 166-176.

Unit 2. Setting the scene: learning disability and society

Social support

A third process that may affect (positively or negatively) psychological well-being is **social support**.

Developing and maintaining relationships with other people is one of the most important factors in psychological well-being and quality of life. For anyone (with or without a learning disability), the presence of a positive social network can protect against the development of psychological problems even in circumstances in which life events, such as the death of a close relative, might otherwise lead to difficulties.



Key psychological concept

Social support

Social support is the perception (and reality) that one is cared for and has assistance available from other people and is part of a **supportive social network**. Supportive resources can be emotional (nurturance, for instance), tangible (financial assistance), informational (advice), companionship-related (sense of belonging) and intangible (personal advice).

Social networks are restricted for many people with learning disabilities. Research has shown that this is the case even when compared to the social networks of people with physical disabilities. Social support for people with learning disabilities is more likely to be provided by family members and carers, with relatively few relationships with people who do not have learning disabilities.

The loss of a relative, or even the move of a professional carer to another role, can therefore have a greater impact upon a person's level of social support and psychological well-being than it would for someone without a learning disability.



Learning activity 2.6

- Think of a client you know well and list the people with whom he or she has relationships. This may include professionals such as social workers or nurses as well as friends and family.
- Write down what kind of relationships they are (for instance, “professional”, “friendship”, “partner”).
- Then do the same for yourself.
- How do the networks compare?
- Can you give some of the reasons why people with learning disabilities may have lower levels of social support than people without learning disabilities?
- What could you suggest to support a person with a learning disability to increase his or her social network?

Unit 2. Setting the scene: learning disability and society

Psychological resilience

Although everyone (not just those with a learning disability) will have difficult issues to cope with in their lives, such as bereavement or conflict with others, it's worth remembering that only a minority of people experience ongoing psychological difficulties. It is thought that the process of **psychological resilience** is key to determining whether enduring psychological difficulties develop, or not. People around the person, such as support staff or parents, can be part of psychological resilience, in addition to the person's individual resources (such as coping strategies).



Key psychological concept

Psychological resilience

Psychological resilience is an individual's tendency to cope with stress and anxiety. It is not only a personal trait related to coping strategies, but also involves a process that includes the individual's ability to take advantage of things around him or her that may be helpful (such as offers of social contacts) and positive environments (including supportive families).

Psychological resilience is an important concept and links with **psychological formulation**, something we will discuss in Unit 4. Psychological interventions will often involve people other than the client who may be able to provide support or help that can increase a person's psychological resilience.

Unit 2. Setting the scene: learning disability and society

Section 3.

Capacity



Learning outcomes

By completing this section, you will:

- understand the concept of capacity to consent and be able to describe the potential impact of learning disability upon this.

Capacity to consent

A diagnosis of a learning disability can raise questions about a person's ability to consent to various things, such as medical treatment and sexual relationships. The assumption used to be that capacity was an "all or nothing" concept and that most people with learning disabilities lacked the capacity to make decisions for themselves. The situation has now changed, with an acknowledgement that people who may not have capacity to do some things, such as managing their finances, may nevertheless be able to consent to other things, like engaging in a health intervention.

Some specific psychological issues can affect the validity of any assessment of capacity. These are particularly relevant for people with learning disabilities, but will also apply to the wider population. They are significant when considering a person's capacity to understand – and agree – to participate in psychological therapies.

First, it's important to distinguish between consent, compliance and coercion. In relation to psychological therapies:

- **consent** means the person "agrees to participate in a joint venture with a therapist which we could label as treatment"
- **compliance** means the client "does as the therapist requests"
- **coercion** means "the process of getting the client to do as the therapist requests by saying that something unpleasant will happen if the request is not followed".

Key psychological issues that can affect how a person will respond include:

- **suggestibility** – the person is more susceptible to "leading" questions: he or she might be persuaded to agree with someone else's point of view, even if previously he or she disagreed; an example would be, "You said that you didn't feel any better, but I think you do feel better. So, tell me, are you feeling better?"
- **acquiescence** – the person says "yes" when asked questions, even if he or she does not necessarily agree: for example, "So, it's okay that I come to see you at home again next week?"

People with learning disabilities can be particularly vulnerable to suggestibility and acquiescence. The power imbalance between someone with a learning disability and a professional such as a doctor or social worker can also increase their effect. Most people, even those without a learning disability, have a tendency to agree when they do not fully understand a question they are being asked. The likelihood of not understanding a question and simply answering "yes" is even greater for someone who has difficulties with comprehension.

Unit 2. Setting the scene: learning disability and society



Learning activity 2.7

Case study: Robert

Robert meets a woman he likes in the local pub in which he is now a regular. They have a few drinks together and go to the cinema a few times. The woman is a bit older than Robert and does not have a learning disability. Robert is very attracted to her and starts talking to her about having a sexual relationship. The woman consents to this: however, some of the older men in the pub are suspicious of the woman's motives and think she may be allowing the relationship to develop so she can extract money from Robert.

They contact the local social work department, and Robert's social worker, Maureen, speaks with him and his parents. Maureen then calls a case conference to discuss whether Robert has capacity to make a decision regarding this relationship.

In the case conference, all those involved in providing a service to Robert are asked about their views regarding his capacity and a capacity assessment is made. The issue of Robert's parents or the local authority

applying for welfare guardianship (powers to decide with whom he consorts) to prevent him from meeting with the woman is raised due to concerns that the woman may be seeking to exploit him financially. But Robert tells everyone at the meeting that he feels his parents and everyone else are trying to stop him "growing up" and that he loves the woman.

- **What factors could influence Robert's decision to have a relationship with this woman?**
- **What factors should be considered when Robert is interviewed as part of the assessment of capacity?**
- **Consider the psychological impact on Robert if it was decided that he does not have capacity to make decisions regarding relationships.**

The discussion then moves to whether Robert is subject to financial exploitation and should be protected under the Adult Support and Protection (Scotland) Act.

Unit 2. Setting the scene: learning disability and society



Further reading

You can find more information about capacity and consent in the following sources.

- NES (2012). Think Capacity, Think Consent: Supporting Application of the Adults with Incapacity (Scotland) Act 2000 in Acute General Hospitals. Edinburgh: NES.
- NES (2011) Respecting and Protecting Adults at Risk in Scotland – Legislation and Practice: an educational resource. Edinburgh: NES.
- Mental Welfare Commission (2011). Consenting adults? Edinburgh: Mental Welfare Commission.
- Scottish Government (2008). Adults with Incapacity (Scotland) Act 2000: A short guide to the Act. Edinburgh: A Scottish Government.



me...



Unit 3

Living with a

learning disability

Unit 3. Living with a learning disability



Learning outcomes

By completing this unit, you will:

- appreciate, and be able to discuss, the psychological effects of lifespan issues that can arise for people with learning disabilities, their families and other carers.

Section 1.

Communication



Learning outcomes

By completing this section, you will:

- identify and discuss communication difficulties and solutions
- identify and discuss the psychological effects of communication difficulties.

“ I didn't like going to meetings about me. There was always a lot of people talking fast. I couldn't remember their names. I used to get really worried and didn't want to go. Now things are a lot better. I have someone who helps me to write down my questions. They help me to ask my questions and make sure that people use words that I understand. They talk to me after the meeting to make sure I understand. I don't feel so worried. I know what people mean now. ”

Richard

Communication

Communication is central to every person's life. It allows us to control our existence, make friends and build relationships, and meet the basic need for interacting with other people. In addition to verbal communication, more subtle non-verbal cues allow us to communicate with each other.

Unit 3. Living with a learning disability

Anxiety, frustration, anger and, in some cases, a sense of **hopelessness** can result if people are unable to communicate effectively. These can be compounded by problems in developing social contacts or engaging in activities. Communication difficulties can therefore have profound psychological effects.

Up to 90% of people with learning disability have communication difficulties, with half having significant difficulties. This may be due to intellectual impairment leading to problems understanding and processing information, sensory or articulation difficulties or **social communication disorders** (which we will discuss in this unit), such as autism spectrum disorders [ASD].

Communication difficulties may be more obvious in people with profound learning disabilities than those whose disabilities are less significant. Difficulties with verbal comprehension and expression and the understanding of non-verbal communication are nevertheless extremely common in people with mild-to-moderate learning disabilities. Literacy and numeracy are also areas of significant difficulty for many. Experience of these can lead to social anxiety and isolation and can erode self-esteem.

People with learning disabilities may struggle to report their feelings, making it more difficult to identify emerging psychological problems (this is discussed further in Unit 4). Supporting people to communicate effectively is therefore not simply a matter of understanding their wishes, but is also essential to promoting their psychological well-being.



Learning activity 3.1

The video clip you can access at:

→ <http://www.youtube.com/watch?v=7k-1FwTBtlc>

shows the effects of introducing a new communication technique to someone with learning disability and complex needs.

- Watch the clip. Consider the psychological effects on someone if they are unable to communicate.
- How can you, as a practitioner, assist someone with profound and multiple learning disability overcome this challenge?
- If you are unable to access the video, you should still reflect on the questions above.



Learning activity 3.2

- How would you usually find out about (or assess) a client's communication skills?
- Have you worked with someone for whom you believe communication difficulties had an effect on his or her mental health?

Unit 3. Living with a learning disability



Further reading

You may find these resources on communication helpful.

- **Communication Forum Scotland**, an informal alliance of organisations representing people of all ages with varied communication support needs:
→ <http://www.communicationforumscotland.org.uk/>
- The Royal College of Speech and Language Therapists' **Adult Support and Protection Communication Toolkit**:
→ http://www.rcslt.org/asp_toolkit/adult_protection_communication_support_toolkit/welcome
- Nicola Grove and Barbara McIntosh's **Communication for Person-centred Planning** resource:
→ http://www.learningdisabilities.org.uk/content/assets/pdf/publications/communication_p_c_planning.pdf
- **Talking Mats** are a way to gather people's thoughts and opinions about different topics. You can find out more information from:
→ http://www.scottishhealthcouncil.org/patient__public_participation/participation_toolkit/talking_mats.aspx
- du Feu, M. & Fergusson, K. [2003]. Sensory impairment and mental health. *Advances in Psychiatric Treatment*, 9, 95–103. This article talks about the mental health issues associated with a hearing impairment, but is still relevant for communication problems generally.

Professionals may over- or underestimate a person's communication skills, leading to increased anxiety and frustration when communication is not adapted to his or her ability levels. In such cases, the issues of **suggestibility** and **acquiescence** [as we discussed in Unit 2] can become particularly relevant.

Assumptions that individuals with learning disabilities cannot be relied upon to give accurate accounts of events may nevertheless persist. This is a particular issue in situations where a person may have been the victim of, or witnessed, a crime. Again, this can lead to frustration and, in some cases, anger that no action has been taken. Anxiety may also be an issue if the person feels that he or she is not being protected against a perpetrator.



Learning activity 3.3

Case study: Christina

Christina is shopping with her carers. She goes to the toilet on her own while her carers carry on shopping. Two women who have been drinking are in the toilet. They close the toilet door to prevent anyone coming in and steal Christina's bag, then leave the toilet and the shopping centre.

They threatened Christina that something bad would happen to her and her family if she reported them. Christina is terrified. She is too scared to leave the toilet and eventually the workers come looking for her. Initially they can't get Christina to say anything, but notice that her bag is missing. Eventually, Christina tells them it has been stolen.

Unit 3. Living with a learning disability

Learning activity 3.3 (continued)

The carers and Christina go to the store manager and the police are called. The police manage to help Christina tell them that two women stole her bag; she can't say any more.

Police check CCTV cameras and there is footage of the women leaving the store. Although they have this footage and Christina's positive identification, the Procurator Fiscal decides not to proceed against the women as he judges that Christina's witness statement would not be reliable.

Consider the above.

- What aspects of law might have helped Christina?
- Is there anything else the Procurator Fiscal could have done to try and ascertain whether he could proceed with this case?
- What psychological effects might this incident create for Christina?



Further reading

- People with Learning Disabilities and Communications Services Qualitative Research Report:
→ <http://stakeholders.ofcom.org.uk/binaries/research/consumer-experience/disabilities.pdf>

Social communication disorders

As we noted before, communication is not simply about speech. The more subtle aspects of communication, such as tone of voice or the context in which something is said, can be just as important as speech to understanding what another person is trying to communicate.

A group of communication disorders, called **social communication disorders**, affect how a person understands this more subtle type of communication.

Autism Spectrum Disorder (ASD) affects how a person communicates with, and relates to, other people and how they make sense of the world around them. ASD is more common in people with learning disabilities than in the general population. Definitions of different types of autism are shown in Box 3.1.

Box 3.1. Definitions of different types of autism

Autism: when a person has a learning disability and lifelong clinical features of autism, which include a delay in the development of language.

High-functioning autism: where the person's intellectual functioning falls within the "normal" or expected limits for the general population, but he or she has lifelong clinical features of autism and experienced a delay in the development of language.

Asperger syndrome: where the person's intellectual functioning falls within the "normal" or expected limits for the general population, but he or she has lifelong clinical features of autism and did **not** experience language delay.

Unit 3. Living with a learning disability

Theory of mind and **central coherence** are psychological theories that relate to communication. They are used to describe how people with an ASD might experience the world and explain some of the behaviours people may exhibit.



Key psychological concept

Theory of mind

This is the ability to attribute mental states (such as beliefs, desires or intentions) to oneself and others: that is, the ability to see the world through someone else's eyes and to take others' points of view into consideration. Theory of mind is essential in understanding and predicting much of human behaviour. Without a theory of mind, the social world can seem chaotic, confusing and even frightening, and we may not be aware of the effect of our actions on others.

Problems with **theory of mind** can lead to people:

- appearing self-centred, talking about their own interests, interrupting others and not showing empathy
- being less willing to communicate with other people because they find it anxiety-provoking as they cannot guess how others will react
- making inappropriate comments, possibly being “too honest” [“Do you like my new haircut?” – “No!”]
- using routines (including rehearsed routines of conversations with others) to give a sense of predictability to an unpredictable, confusing world.



Key psychological concept

Central coherence

There is usually too much going on in the world (sights, sounds, feelings) for us to take in all the information about a situation. We therefore filter out certain information and focus on what is relevant. This is central coherence: the ability to form a cohesive whole out of all available details.

Weak central coherence can lead to:

- people focusing excessively on details and becoming upset when there are small changes to their environment
- hypersensitivity to stimuli: the person is unable to filter out all of the stimuli so becomes “overwhelmed”
- inability to generalise things that have been learnt, particularly social skills that people have practised.

Unit 3. Living with a learning disability

The combination of these difficulties may explain why some people with an ASD struggle with social situations. Anxiety in social situations is common among people with an ASD due to **difficulties in understanding others' intentions** (as in theory of mind) and **potential sensory overload** (as in central coherence theory) when communicating with others.

Anxiety can lead to withdrawal from social situations, resulting in reduced social contacts and the loss of occupational and educational opportunities. Diagnosis of mental illness can be particularly difficult in people with ASD, partly because many people struggle with social contact; withdrawal from activities is therefore not always immediately evident.

People with ASD often find it difficult to identify or “label” emotions within themselves and express these to others. Again, the effects on psychological well-being can be substantial.



Further reading and information

- Tager-Flusberg, H. (1999). A psychological approach to understanding the social and language impairments in autism. *International Review of Psychiatry*, 11, 325–334.
- **The National Autistic Society:**
→ www.autism.org.uk

Section 2.

Transitions



Learning outcomes

By completing this section, you will:

- identify and discuss the psychological effects of key transition points for people with learning disabilities
- identify and discuss issues of relationships and sexuality that people with learning disabilities may face, and how these issues can affect some people psychologically.

Leaving school

Transitions can occur at various stages throughout life. We use the term “transition” in this section as applied to the planning process that should take place for someone with learning disabilities when he or she moves from child to adult services. All young people have dreams, aspirations and ambitions at this time of their lives. This is no different for people with learning disabilities, but some may need help to identify what these are and support to overcome barriers they may face in reaching their potential.

Unit 3. Living with a learning disability

Families are also affected by the transition process. The practicalities of this life stage can cause additional stress to families, who must deal with legal considerations, financial issues, changes in caring roles and the practical aspects of life, such as further occupation or education. Parents of a young person with learning disabilities can sometimes be reluctant to accept that their child is now a young adult, particularly in relation to sexuality and relationships. When parents fail to accept their son or daughter is reaching adulthood this can cause emotional upset and tension for the whole family.



Learning activity 3.4

You should reflect on this activity on your own.

- Think about a life-changing event in your own life. Try and remember your thoughts and feelings at the time (write them down).
- Now think about your present thoughts and feelings on the same situation. Do they differ?

Unfortunately, the transition process can sometimes become a “practical problem-solving” exercise, with “problems” becoming the focus for planning. This can lead to the emotional and psychological needs of the young person being left in the background. The potential **increased expectations on parents** can also cause significant stress and affect relationships within the household. We talk about these issues later.

Young people's responses to these changes in their life may include feelings of fear, anxiety, indifference, anticipation, resentment, guilt, excitement or pleasure. **Young people making the transition from adolescence to adulthood may feel that their family are making decisions without consulting them and hence develop a sense of learned helplessness.** Making the person aware of the fact that they have rights can increase his or her self-confidence and self-esteem and allow them to exercise more control over their lives. Support from an independent advocate can also help to ensure young people's wishes are heard and provide support to ensure their rights are respected.



Learning activity 3.5

Case study: Michael

Michael entered his final year of schooling when he was 18. Until that time, his parents had become used to the routine and support of the school environment. Michael's health care was also being changed, with paediatric services no longer being involved. He would now be dealt with via general medical services and the adult learning disability team.

Michael always seemed to like school. He would be more frustrated during the holidays, often becoming very vocal and “fretting”. He spent some time in a respite holiday placement, which he also seemed to enjoy, but he would be unable to access this facility after he left school.

Michael and his parents were invited to a transitions meeting a few months before he left school. His parents were shocked at the lack of provision for people moving on from school. The maximum service available was three days at a day centre with no other provision on offer. No one was sure what Michael thought about this.

Unit 3. Living with a learning disability

Learning activity 3.5 (continued)

- Discuss the role of health staff in a transition meeting. Is there anything they can offer?
- What are the potential psychological effects of this transition on Michael and his parents?



Further reading

- The Doran Review made recommendations for the provision of services to support young people with complex needs in education. You can access this at:
→ <http://scottishtransitions.org.uk/the-doran-review/>
- The Scottish Transitions Forum has produced a short video explaining the rights of children:
→ <http://scottishtransitions.org.uk/your-rights-simplified/?topicfrom=your-rights>

Relationships and sexuality

“ I wanted to have a boyfriend but Mum and Dad wouldn't let me. They are scared that something bad might happen. I've got a boyfriend now. We go for lunch. My worker always comes with us when we are having lunch. Mum and Dad like that. I want me and my boyfriend to be on our own.”

Joanne

As we discussed in Unit 2, social networks of people with learning disabilities are often more limited than those of people without learning disabilities. This can lead to fewer opportunities to socialise, develop loving relationships and meet sexual needs.

Parents may find it particularly difficult to accept that their child wishes to form relationships. Their fear of exploitation or misinterpretation of the child's actions can lead to anxiety which, in turn, leads to greater restrictions being placed on the child's opportunities to express his or her sexuality. Frustration and anger consequently emerge. The professional role may be to explore these issues with the person with a learning disability and (depending on consent being given by him or her) support carers to recognise that he or she may be interested in forming close relationships.

People may choose to share their feelings about their sexual and emotional needs with their care worker or professional staff. It can be difficult for family carers to acknowledge the person's right to privacy and to receive appropriate information.

Development of sexuality and independence is critical for adolescents, particularly at the time of transition to adulthood. There can be a greater risk of inappropriate relationships and sexual behaviour if restrictions are in place. People may become frustrated when they see siblings or peers developing relationships and apparently “overtaking” them.

Unit 3. Living with a learning disability



Learning activity 3.6

Case study: Robert

Robert's younger sister has recently moved to another city to go to university. She returned for the Christmas holidays with her new boyfriend. She is talking about moving into a flat with him in second year of university.

Either by yourself, or with your mentor, reflect on and take notes on the following.

- What kind of emotions might Robert be experiencing?
- What kinds of behaviour might you see from Robert?
- What kinds of things would be important to enable Robert to be supported through this experience?



Further reading

- Pownall, J., Jahoda, A. & Hastings, R. [2012]. Sexuality and sex education of adolescents with intellectual disability: mothers' attitudes, experiences, and support needs. *Intellectual and Developmental Disabilities*, 50, 140-154.
- NHS Lanarkshire has a series of easy-read materials on sexual health and other health issues. These can be found at:
→ <http://healthelanarkshire.co.uk/sexual-health-information>



Video Story



This video clip shows a group of people discussing the importance of relationships and some of the barriers they have faced in developing friendships and intimate relationships.

Unit 3. Living with a learning disability

Section 3.

Carers



Learning outcomes

By completing this section, you will:

- identify and discuss how stress within a family or support team might affect relationships between family members or staff
- consider issues of carer stress and identify means of supporting carers with stress.

Carers' roles

Family carers or paid support workers are an invaluable part of the lives of many people with learning disabilities. They provide day-to-day practical care for people with more significant physical needs and facilitate people to undertake various daily activities, including accessing education, recreation and occupational opportunities in the community.

Despite this, issues around carer stress and the potential for people with learning disabilities to feel they have little control over carers' inputs should not be forgotten. The issue of **learned helplessness** may also arise. Individuals transitioning from adolescence to adulthood may feel this perceived over-involvement of family carers most acutely.

Family carers

“ I don't think people would realise how hard it is, looking after him. It's the thing that worries me the most. If I wasn't here. I lie awake thinking if something happens to me who'll look after him, because I'm the one trying to hold it all together.”

Maggie

Family carers comprise the largest source of support. Around 60% of people with learning disabilities reside with their families, who take on some form of caring role.

While carers typically report this to be a positive experience, researchers have found that the caring role can present long-term challenges, with higher levels of stress and depression. Family carers may also feel more isolated, as sharing social activities with peers can become difficult. Those who care for adults with learning disabilities who present with behaviour that challenges can be at particular risk of experiencing such difficulties.

Difficulties can increase over the years as family support networks of friends and relations gradually reduce. The breakdown of family care is often the reason behind an individual being admitted to residential care.

Pearlin et al (1990) drew up a framework to identify caregiver demands and resources. This was primarily for carers of people with Alzheimer's disease, but can also be applied to caring roles more generally. **They distinguished four domains:**

- **background and contextual factors:** such as age, life-history and financial status

Unit 3. Living with a learning disability

- **stressors:** primary (directly connected with giving care), secondary (conflicting demands of caring, work and family) and secondary “intra-psychic” strains (such as the impact of caring on self-esteem)
- **mediators of stress:** resources for coping with stress
- **outcomes:** for both the individual and carer.



Further reading

- MacLennan, W. [1998] Caring for carers. *Age and Ageing*, 27, 651–652.
- Pearlin, L. et al [1990]. Caregiving and the stress process: An overview of concepts. *Gerontology*, 30, 583–594.



Learning activity 3.7

Case study: Michael

After Michael left school and started at a local day centre, his parents took some time to get used to the new routine and to cope with the fact that Michael had more free time that they had to help him fill.

His parents each worked when he left school, although his mum decided to reduce her hours to try to support Michael a bit more. She had worked as a legal secretary and so set about finding out exactly what Michael was entitled to. She managed to get independent-living funding for him and made sure his benefits were maximised so he could get as much as possible. She was also aware that neither she nor her husband could continue to provide the level of physical care that had been possible when Michael was a child, as he was getting larger and heavier and they were getting older.

Michael's parents are now both in their early 60s. Mum retired at 60, but Dad is still working full time. They still receive the independent-living funding, which pays for support to take Michael to concerts and the cinema and allows for two holidays per year for him with paid carers.

Michael's mum is secretary of the local Enable branch and has made friends with a number of parents who have sons and daughters with learning disabilities. She has been very assiduous in seeking support to ensure their house had adaptations to lift Michael comfortably and help with all aspects of his daily care routine.

Unit 3. Living with a learning disability

Learning activity 3.7 (continued)

Michael's dad does not get involved in Enable or the other clubs his mum has joined. He prefers more family-oriented or solitary activities: he enjoys walking and bird-watching and will often take Michael for walks in the local country park.

He recently had a cardiac arrhythmia diagnosed and has to be a bit more careful about physical work. A pacemaker may be required. Michael's mum has type 2 diabetes, diagnosed after a well-person check at her doctor. Dad plans to retire in three years.

Consider Pearlin's framework above.

- Write down the demands on Michael's family carers and the resources they have to deal with this.
- What do you think are the family's main concerns at this time in their lives?

Paid carers

Just as for family carers, research has shown that people working in services for people with learning disabilities can experience high levels of stress, to the point that some staff will develop mental health problems. This is even more likely to happen when the service is provided for people who present with challenging behaviour.

Staff stress can lead to:

- absenteeism and sickness
- a high turnover, creating inconsistency in care
- negative attitudes toward the people being supported.

Researchers looked at the effects on paid carers of working with someone with challenging behaviour and found that self-injurious behaviour is more likely to produce emotions such as fear, sadness and despair than aggressive behaviour, which evokes emotions of annoyance and anger. Explanations for the challenging behaviour can affect how carers respond and the effects on their psychological well-being. This is termed an **attribution** – what the behaviour is attributed to.

Attributions can affect how we feel and how we respond to people. For example, if we have a child who refuses to go to school, we might attribute this to anxiety about school and be sympathetic, changing our response to the behaviour. If we attribute the child's refusal to a wish to remain at home and play a computer game, our response may generate feelings of frustration and we will be less sympathetic. The child's behaviour remains the same, but our emotional response and behaviour may be altered by the attribution we have made.

Unit 3. Living with a learning disability

In the same way, the attributions that professionals (such as support and health staff) make toward challenging behaviour (for example, whether the behaviour is intentional or outwith the control of the person) significantly influence the emotions they feel and how they respond. Anger toward the person may develop if it is felt that the behaviour is intentional.

The psychological factors of carer stress, attitudes toward the client and attributions toward behaviours are therefore key factors in determining the support a client will receive and will influence his or her well-being, quality of life and any challenging behaviours they may present.



Learning activity 3.8

Case study: Michael

Michael's parents have noticed that recently he has been up a lot during the night. Technology in his bedroom that was initially put in place because of nocturnal seizures alerts them to movement. He has also started to refuse to eat and has been incontinent. When his parents try to encourage him to eat, he starts to shout at them and throws the food away.

Michael's behaviour has also changed at the day centre. He has been refusing food at lunchtime and has screamed and started hitting out when staff try to assist him with personal care. Staff consequently have struggled to support him: one staff member has been struck and injured on two occasions and believes that Michael is specifically "targeting" her. She does not wish to support him anymore, but because of staff shortages, the manager cannot guarantee this: she will therefore have to support him from time-to-time.

His parents have become very worried about him and feel that his behaviour has a physical cause. Day centre staff believe that Michael is trying to tell them that he does not want to be at the centre. They met with his parents and social worker and suggested he move to another day placement.

- **Consider the explanations that Michael's parents have given for the change in his behaviour. What are their attributions? How might the emotions they experience affect their behaviour toward him?**
- **Consider the explanations that staff at the day centre have given for the change in his behaviour. What are their attributions? How might the emotions they experience affect their behaviour toward him?**
- **How would you manage this situation and explore the attributions of Michael's parents and staff?**
- **At what point would you consider referring Michael to another discipline or service? Which discipline or service would you refer to, and what would you expect from them?**

Unit 3. Living with a learning disability

Section 4.

Sexual abuse



Learning outcomes

By completing this section, you will:

- have knowledge of potential indicators and psychological effects of sexual abuse against people with a learning disability
- identify and describe possible means of supporting people who have experienced sexual abuse
- identify and describe when referral to other professionals would be necessary.

Sexual abuse and its effects

Sexual abuse may consist of any sexual activity to which an individual does not, or cannot, consent. It can take a variety of forms, including rape, penetration, touching, indecent exposure and forcing someone into watching sexual acts. Some sexual activity is illegal because of the relationship between those involved. It is against the law for staff involved in the care of an individual to have a sexual relationship with him or her.

It is difficult to be clear about the extent of sexual abuse against people with learning disabilities, but research suggests that it often remains unreported in the general population; there may be particular risk factors that make people with learning disabilities more vulnerable and even less likely to be able to report such abuse.

It is often people who know the person well, such as family carers or experienced staff members, who will be aware of changes in a person's behaviour. It should also be borne in mind, however, that the most likely perpetrators of abuse are generally those closest to the person: there are far fewer instances of abuse or sexual assault perpetrated by strangers.



Learning activity 3.9

You have been asked to provide training to a staff team on identifying the signs and effects of sexual abuse on people with a learning disability.

- **Identify the particular factors that may place people with a learning disability at greater risk of sexual abuse than someone without a learning disability.**
- **Identify the signs of sexual abuse that staff should be aware of and the potential effects of abuse on a person with a learning disability.**
- **Write down the advice that you would give staff on managing disclosures of abuse from clients.**

Unit 3. Living with a learning disability

Learning activity 3.9 (continued)

You may wish to read **Unlocking Sexual Abuse and Learning Disabilities. Supporting adults with learning disabilities who have been sexually abused: a guide for family carers and support staff** to assist you in completing this learning activity. You can access this at:

→ http://www.bava.org.uk/wp-content/uploads/enable_abusebooklet_handbook.pdf

Psychological interventions for abuse

Research on the general population has shown that some psychological interventions can be helpful in allowing people to manage difficulties that may result from sexual abuse. Interventions include anxiety management, graded exposure to anxiety-provoking situations (such as sleeping alone in a bedroom) and cognitive restructuring, which is often used to support people to gain a view that they were not responsible for the abuse.

Similar interventions may also be of benefit for people with learning disabilities, although cognitive restructuring may only be appropriate for people with mild-to-moderate learning disabilities.



Further reading and information

- **Out of Sight** report:
→ www.mencap.org.uk/sites/default/files/documents/Out%20of%20sight_report_0.pdf
- The Scottish Government guide, **Being a Witness – helping people with learning disabilities who go to court: a guide for carers**:
→ www.scotland.gov.uk/Resource/Doc/152441/0040998.pdf
- The Scottish Government's **Information and Help after Rape and Sexual Assault**:
→ www.scotland.gov.uk/Resource/Doc/220190/0059149.pdf
- The ENABLE Scotland easy-read booklet, **Surviving Sexual Abuse: what you can do if you think you have been sexually abused**:
→ www.enable.org.uk

Unit 3. Living with a learning disability

Section 5.

Bereavement and loss



Learning outcomes

By completing this section, you will:

- have knowledge of, and be able to describe, how grief might be expressed by a person with a learning disability
- be able to identify and discuss the factors that affect the grieving process
- have knowledge of possible means of supporting a person who has experienced a bereavement
- have knowledge of when referral to other professionals would be necessary.

Normal and complicated grief

“My mum had just died. I went into hospital the same day. They said I needed looking after. I was very sad. They kept wanting me to dance.”

Orwin, 1991

Everyone experiences loss at some point in their lives, with death usually perceived as the ultimate loss. For most people, coping with loss happens with help and support from friends, family and others close to them. There are thought to be several “tasks” that are necessary to complete the process of mourning, although these are not always done in the order outlined:

- accept the reality of loss
- work through the pain
- adjust to the environment in which the deceased person is missing
- accept that the deceased person is no longer in the same place in your life.

Some people, however, may experience “complicated” or “abnormal” grief. This may manifest as the person:

- experiencing grief for much longer than would be expected
- not showing any signs of grieving at all, or feeling “numb”
- being overwhelmed by his or her feelings
- developing other symptoms that other people don’t see as being related to his or her loss.

Unit 3. Living with a learning disability

Expressions of grief in people with learning disabilities

It used to be assumed that people with learning disabilities did not grieve because they lacked the cognitive (intellectual) or emotional capacity, or did not form the same attachments to other people as those without learning disabilities.

It is now accepted that people with learning disabilities go through the same stages of grief as anyone else, with each person's reaction being as individual as that of anyone without a learning disability. In some cases, however, differences in the way that **some** people with learning disabilities grieve may be seen.

Grief may be delayed, and some bereavements can lead to multiple losses/ life events. For example, if a parent who is also a person's main carer dies, a number of consequences may accrue – in addition to losing mum or dad, the person has also lost his or her carer and possibly a significant point of social contact. Additionally, there may be some circumstances (as with Christina) in which the death of a parent can lead to the loss of a home and contact with the family, leaving the person particularly isolated.

It is still the case that the reactions of people with learning disabilities are sometimes not acknowledged. Carers may be struggling with their own grief or are unsure about how to respond to the person they care for. There may also be times when “diagnostic overshadowing” might lead to grief reactions being seen as a sign of other problems. This can be a particular problem when someone is unable to communicate verbally.

Non-verbal ways of showing grief include:

- clinging – not wanting to sleep alone
- reluctance to go out
- being incontinent when this is not usually a problem
- self-injury
- destructive behaviour
- restlessness
- aches and pains
- changes in sleep patterns
- changes in appetite
- apathy or tiredness
- minor illness
- clumsiness and accidents.

Coping with the death of another person

Several factors affect how any person copes with the death of someone. A learning disability may affect how a person understands these factors and how other people treat them. The following factors have been found to be important:

- understanding of death
- preparation for the death
- participation in bereavement
- communication skills
- the relationship with the person.

Unit 3. Living with a learning disability



Learning activity 3.10a

Case study: Christina

We return in this learning activity to the time before Christina was admitted to long-stay hospital, when she was still living at home with her parents.

When Christina was 29, some things started to change at home. Her mum stopped going out as much with her friends and didn't take Christina shopping. Sometimes, she would simply go away: dad would take a day off work and go with mum while one of Christina's sisters came to look after her.

Sometimes Christina saw her dad crying in the kitchen. When she asked him what was wrong, he told her he'd been peeling onions.

One day, Christina's mum went into hospital. She wasn't able to come to Christina's 30th birthday party. Christina wasn't allowed to visit mum in hospital: her sisters took turns at staying with her.

Christina's dad was at the hospital most days. He took some time off work. One day, he came home and told Christina: "Mum's away up with the angels". Christina didn't really know what that meant.

A week later, Christina had to go and stay with a relative in England for a week. Everyone had been at her house but she wasn't allowed to be there.

After she returned home, dad took her to a park where there were lots of stones and plaques and showed her a place where lots of flowers were on the grass. He told Christina that her mum was resting there. Christina thought her mum was with the angels and wasn't sure why she would be resting on the grass. She started to pick the flowers up to see where her mum was. Her dad told her to stop this.

Dad went back to work after a few weeks. Her sisters didn't come around as often. Christina went to a Day Centre and people looked after her when her dad was at work. Christina really missed her mum.

About a month after dad went back to work, a woman and a man came to Christina's house. Dad stayed off work to see them. They spoke to dad, showed him pictures and then took Christina in a car to a big old building where lots of other people lived.

Christina had to share a bedroom with five other women and sometimes the women shouted and swore, hit her and stole her sweets. Her dad visited once and she didn't see him again.

Just after Christina turned 46, her sister came to visit her and told her that dad had died. She took Christina to the funeral and Christina was able to see a lot of her family again.

- **Consider how Christina might have felt when her mother was ill and she didn't know what was going on.**
- **Write down the things that might affect Christina's ability to work through the different tasks of mourning.**

Unit 3. Living with a learning disability



Learning activity 3.10b

Case study: Christina

Many years later, Christina is now living in her own tenancy with carers. One of her carers spent a lot of time finding out about Christina's past and put together a book about Christina and her family. Christina knows her mum and dad are dead, but she still gets a bit confused about some of the things she was told at the time. She will often say that her mum is "resting" under flowers.

Margaret, Christina's main carer, has been off sick for a few weeks. She doesn't come back to work, but visits Christina and tells her she has an illness called stomach cancer. She tells Christina she has to go for an operation and get medicine to help her get better and she'll probably not be back to work with Christina for a long time. She promises Christina that she will let her know how she is getting on with her treatment.

After about five months, one of Christina's carers tells her Margaret is very ill. The operation and the medicine have not helped the stomach cancer. It's getting worse and Margaret is not going to get any better. Christina is very upset – she tells the carers she wants to see Margaret. The carers aren't sure, but ask Margaret and her family. They all say that it is okay for her to visit.

Christina visits Margaret at the hospice and can see she is very ill. Margaret can't talk for very long. Christina hugs her and says goodbye. She cries all the way home.

She asks the other carers if Margaret is going to die and they tell her that she will. They help Christina find pictures and things that remind her of Margaret and they make up a box with all the memories in it. Two weeks later, Margaret dies. Christina goes to the funeral and is welcomed by Margaret's family.

Christina and her workers raise some money to plant a tree in the local park to remember Margaret by. It has a plaque with her name on it and Christina can go and visit it whenever she wants to.

- **List the things you think made the second experience of death very different for Christina.**
- **Do you think this experience would make it easier for Christina to work through the tasks of mourning? If so, why?**

Although this experience seems to have been better, it might trigger some of the memories Christina has of her mother's illness and death.

- **What would you do if Christina starts to become distressed or shows changes in behaviour that might be related to grief?**
- **Would you do these things alone or would you involve other workers/professionals? If the latter, who would you involve, and why?**

Unit 3. Living with a learning disability

Supporting clients to cope with bereavement

We should allow a person who has lost someone close to talk about their loss, if they are able to talk, ask them questions and listen. You could offer words to help them describe their emotions (although be careful not to “put words into the person’s mouth”). It can be helpful to look at photographs or other mementoes of the deceased with the person. This can be very important when people struggle to communicate verbally. Give the person time and be prepared to let him or her ask the same question several times.

Paid carers can facilitate a person’s involvement in events such as funerals and can also highlight times when changes in a person’s behaviour might indicate grief. Individuals may nevertheless have different beliefs about the effects of bereavement on a person with a learning disability. It’s therefore important that staff working with a person who is grieving share a similar understanding of the grieving process for that person. Offering training to a staff team, or a discussion with a family, can be helpful.

Always remember that carers may have had losses in their lives that might affect how they can work with a person. You should be sensitive to this issue and its potential effects on the client and carer.

It is important that professionals communicate with family members, particularly as the death of a parent may lead to greater involvement of siblings. There should be recognition of family members’ emotions and the coping difficulties they may be experiencing.

There may be times when you think that a person needs more help than you can give. You should seek further help when he or she appears to be experiencing a complicated grief reaction, or when you are unsure about how others should be responding to a person’s grief.



Further reading

- Cathcart, F. [1994]. *Understanding Death and Dying*. London: British Institute of Learning Disabilities.
- Orwin, M. [1991]. *Am I Allowed to Cry? A Study of Bereavement amongst People who have Learning Difficulties*. London: Souvenir Press.
- Hollins, S., Sireling, L. & Webb, B. [2004]. *When Mum Died*. London: Gaskell.



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Unit 4

Psychological support

for people with

learning

disabilities



Unit 4. Psychological support for people with learning disabilities

Section 1.

Prevalence of psychological difficulties in people with learning disabilities



Learning outcomes

By completing this section, you will:

- have an understanding of the prevalence of mental health problems in people with learning disabilities
- be able to identify and discuss issues of diagnostic overshadowing in the assessment of psychological difficulties in people with learning disabilities
- be able to identify some of the different ways in which psychological difficulties may present in people with learning disabilities
- be able to identify some of the risk factors for psychological difficulties in people with learning disabilities.

Our aim is to look at some mental health issues with which a person with a learning disability may present. We also introduce psychological formulation and therapy, but as we stressed at the start of the resource, it's not intended to be a manual through which therapeutic techniques can be learnt. Instead, our aim is to raise your awareness of the process of psychological therapies. Anyone delivering psychological therapies should be appropriately trained and supervised.

We use the term “psychological difficulties” in the unit, but revert to the term “mental illness” when we talk about research studies that involve psychiatric diagnosis.

Prevalence of psychological difficulties in people with learning disabilities

Some clinicians in the past argued that a low IQ “protected” against the development of psychological difficulties. It was believed that people with learning disabilities did not have the intellectual capacity to reflect on their own thoughts and feelings, so consequently could not develop conditions such as depression. It was also suggested that the effects of a learning disability were far more debilitating than a psychological difficulty, so psychological difficulties were rarely acknowledged or addressed.

This is no longer the case, with far greater awareness of the possibility that anyone can develop psychological problems. Indeed, research has shown that somebody with a learning disability is at greater risk of experiencing psychological difficulties than a person without such a disability. Risk factors for psychological difficulties in the general population include:

- social isolation
- relationship problems
- adverse life events
- abuse of any form
- chronic physical illness
- care home residency or paid carer support
- poverty.

Unit 4. Psychological support for people with learning disabilities

Each affects a greater proportion of people with, than without, learning disabilities. It should therefore not be surprising that psychological problems may be more common in people with learning disabilities than in the general population. Studies have estimated the rate of mental illness among people with learning disabilities in their lifetime to be between 10% and 50%, in comparison to around 30% of the general population.

As we noted in Unit 2, however, only a minority of people with learning disabilities will develop a mental illness. The process of psychological resilience is key to whether enduring difficulties develop.



Further reading

- The Mental Health Strategy for Scotland: 2012–2015 can be accessed at:
→ <http://www.scotland.gov.uk/Resource/0039/00398762.pdf>



Learning activity 4.1

Case study: Robert

Robert's mum has recently noticed that he isn't going out as much as he used to. He tends to sit in the house, generally watching TV, but sometimes going up to his room and lying on his bed. When mum asks if anything is wrong, Robert says he doesn't know.

Robert used to go the pub and the betting shop quite a lot until he was barred from the latter. Although he enjoys the pub, it seems he can't be bothered going any more. He recently split up with the woman he had been going out with.

Robert's dad has started to get very irritated with him because he doesn't have a shower every day and generally spends his time eating. His mum thinks there might be something wrong with him, but dad says he's fine – all he needs is a “good kick up the backside!” Dad tells Robert he's going to start going with him to football on Saturdays and says that Robert is going to have to do more in the house if he's going to carry on eating as much as he does.

Robert goes to football with his dad, but complains about the cold and the seats. He says he doesn't like football, but dad won't let him give up until he finds something else to do. Mum gets him to go to the shops to pick up milk and papers in the morning but this is a great effort, with Robert trying to avoid it at every turn.

Unit 4. Psychological support for people with learning disabilities

Learning activity 4.1 (continued)

Robert's mum wonders if he might have something wrong with his thyroid. Her dad had thyroid problems and behaved similarly. She takes Robert to the doctor but his thyroid function is fine. The doctor suggests more exercise and getting out to see people.

Robert starts to go out of the house after lunch, saying to his mum he's going to the pub or the gym or to see friends. However, he is going to the library to sit in the comfortable seats. He sometimes watches DVDs there, but mostly falls asleep. He has been asked to leave on a few occasions.

Either by yourself, or with your mentor, consider the following.

- Could anything else be happening to Robert?
- What issues might make it difficult to identify the underlying reasons for Robert's presentation?

Diagnostic overshadowing

Diagnostic overshadowing is when people's presenting symptoms are attributed to aspects of their learning disability, rather than any other possible cause. For example, a person with learning disabilities who becomes withdrawn may not be seen as being depressed, but as someone who doesn't like the people he spends time with. If people are unable to explain or understand their feelings and thoughts, it can be particularly difficult for them to report symptoms of psychological distress.

Diagnostic overshadowing can be a real risk when working with someone with a learning disability, particularly if his or her emotional state varies from day-to-day. It can be difficult in these situations to identify symptoms that might indicate psychological problems. We discuss issues that might arise when assessing the psychological well-being of a person with a learning disability in the next section.



Learning activity 4.2

- Consider someone you've worked with for whom diagnostic overshadowing has been an issue. What was the result for your client, and did it change the treatment he or she received?

Screening and assessment of mental health needs

Assessing the psychological well-being of a person with a learning disability is similar to that of a person without a learning disability, although there are some important differences. For instance, more information may need to be gathered from other sources, such as paid or family carers. In addition, some individuals may find it more difficult to:

- explain how they feel
- describe the development and "history" of their symptoms
- identify events or factors that may have contributed to their difficulties, such as a change in carers, bereavement or abuse
- identify physical health problems that could explain their symptoms, such as chronic pain
- report pain from physical problems such as toothache or deterioration in vision or hearing.

Unit 4. Psychological support for people with learning disabilities

Screening measures

Several screening measures for mental health difficulties have been developed for use with people with learning disabilities, including the Glasgow Depression Scale for People with a Learning Disability (GDS-LD), Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID) and the Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD) [Box 4.1].

Box 4.1. Screening measures for mental health difficulties for use with people with learning disabilities

Glasgow Depression Scale for People with a Learning Disability (GDS-LD)

This is a 21-item questionnaire that is completed with the individual. There is also a questionnaire for carers that asks about symptoms they may have noticed in the person.

Source: Cuthill, F.M., Espie, C.A. & Cooper, S-A. [2003]. Development and psychometric properties of the Glasgow Depression Scale for People with a Learning Disability: Individual and carer supplement versions. *British Journal of Psychiatry*, 182, 347–353.

Glasgow Anxiety Scale for People with an Intellectual Disability (GAS-ID):

This 27-item questionnaire is completed with the individual.

Source: Mindham, J. & Espie, C.A. [2003]. Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research*, 47, 22–30.

The Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD):

This is a checklist of possible symptoms of mental health problems. It is completed with the carers of a person with a learning disability.

Source: Moss, S. [2002]. The Mini-PAS-ADD Interview Pack. Brighton: Pavilion Publishing.

Unit 4. Psychological support for people with learning disabilities



Learning activity 4.3

- Do you use any psychological screening measures in your everyday work? If yes, what measures do you routinely use? If no, are there any psychological screening measures you would like to find?
- If you do use measures routinely, identify which of those you've listed were developed for use with people with learning disabilities.
- Write down the difficulties you have encountered when administering these to some of your clients with learning disabilities.
- How did you overcome any problems?



Further reading

- The computer package “In My Shoes” presents a method of accessing people’s thoughts and feelings about different situations. Although initially developed for use with children, it is equally applicable to working with people with learning disabilities. Details of the package, and training required to use it, can be found at:
→ www.inmyshoes.org.uk



Learning activity 4.4

Case study: Michael

Michael's parents have made an appointment to see the day centre manager as they are concerned about some aspects of Michael's behaviour. They want to know if similar things are happening at the centre and, if so, what staff are doing about it.

Michael has been waking through the night, although he isn't having seizures. It doesn't happen every night, but 2 or 3 times a week. He starts “howling” and can sometimes keep this going for up to an hour. Initially his parents tried all the usual approaches they use to calm him, but none worked. They've found that giving him chocolate can stop the howling, but they aren't too keen on doing this.

In the morning, Michael is described as “obstructive” when his parents try to get him ready. They say he deliberately tries to prevent them from dressing him and his mum is fairly convinced that on a couple of occasions he has purposely kicked out at her. She knows his legs can go into spasm and he can accidentally make contact with people with his feet, but she is adamant the occasions she is referring to have been intentional.

Michael used to really enjoy watching “Grease” on DVD and would try to sing along, but he now loses interest in the film fairly quickly and will sometimes turn his head away from the screen when it is on. His parents have tried to get him to do some of the things he usually likes, but he is less willing to participate.

Unit 4. Psychological support for people with learning disabilities

Learning activity 4.4 (continued)

When his parents take him to the shopping precinct, he no longer wants to go to some of the knick-knack shops he used to like. He sometimes starts to shout and scream when he is out and his parents feel they have no option but to return home, as the screaming can attract a lot of attention from passers-by.

The day centre manager tells them that staff have not noticed a great deal of difference. Michael's keyworker joins the meeting and says they have found him easier to manage recently. He doesn't want to go out as much and is staying in the centre to participate in groups.

When the parents question the keyworker further, he concedes that previously Michael could be quite "lively" and that he sometimes struggled with him when they were out in a group situation. The keyworker also says that Michael is not overly participative in group sessions and has fallen asleep on a few occasions.

The keyworker says he has noticed that Michael isn't eating much. He has never been a particularly big eater, but even on days when he's getting his favourite meals he doesn't seem to be enjoying this quite as much.

Consider the case study above.

- Can you list all the possible reasons ("hypotheses") you can think of that might explain what is behind the change in Michael's behaviour?
- What could you do with Michael, his family and the staff at the day centre to try and identify what is happening for Michael?



Video Story



This video shows people talking about the help they have received from support staff and other professionals.

Unit 4. Psychological support for people with learning disabilities

Personality

Although the idea of “personality” is highly contentious (with arguments about whether personality is “fixed” or changes over time), there is general agreement that people have **underlying “traits” that predispose them to behave in certain ways in different situations.**

It was suggested at the beginning of the 20th century that people with learning disabilities acquired their personalities entirely from earlier generations (through genetics), or that underlying intellectual deficits accounted for all behaviour and personality. It is now accepted that the personalities of people with learning disabilities vary, as is true of the population in general.

Personality disorder is a controversial diagnosis for people with and without learning disabilities. They are described as “severe, persistent and pervasive patterns of cognition, affectivity, interpersonal behaviour and impulse control that deviate from the norm” and can lead to problems with everyday life and social relationships. People with personality disorders often experience a great deal of psychological distress.

Diagnosing personality disorders in people with learning disabilities can be difficult because of:

- diagnostic overshadowing, where a behaviour such as impulsive self-injury may be viewed as a “challenging” behaviour rather than being seen within a framework of borderline personality disorder
- cognitive and communicative impairments
- unusual developmental experiences (such as a person living in a long-stay hospital for much of his or her life)
- a lack of standardised assessments for people with learning disabilities, particularly in applying criteria that depend on identifying thoughts and feelings

- overlaps between criteria for some personality disorders and conditions that are more prevalent in people with learning disabilities (such as schizoid personality disorder and autism spectrum disorder)
- a limited research base.

Although there are concerns that diagnosing a personality disorder in someone with a learning disability may be “doubly stigmatising”, an accurate diagnosis can help in understanding and explaining a person’s difficulties (Box 4.2). It can also point toward potential treatment options for the psychological difficulties with which the person presents.

Box 4.2. Recommendations for diagnosis of personality disorder

Personality disorder should not be diagnosed in people with severe or profound learning disabilities because of the potential influence of cognitive impairment on behaviour and relationships.

It should not be diagnosed before the age of 21, since it is possible that the development of people with a learning disability will be delayed in comparison to the general population.

Schizoid personality disorder should not be diagnosed because of the overlap between the traits of this disorder and autism spectrum disorders.

Avoidant and dependent personality disorders should not be diagnosed because experiences during upbringing, and the need for more support, may overlap with the traits of these disorders.

Any personality disorder diagnoses should be **provisional**, as a change in environment may lead to change in attitudes and behaviours.

Unit 4. Psychological support for people with learning disabilities

Section 2.

Making sense of it all: using psychological theories and formulation



Learning outcomes

By completing this section, you will:

- have knowledge of, and be able to identify, the basic psychological theories that underpin most psychological therapies
- be able to identify the process of formulation and apply this knowledge in the use of psychological theory/models and the “5 Ps” to contextualise a person’s difficulties and provide a basic formulation of a case study
- be able to reflect on how you might share such a formulation with a person with a learning disability and his or her carers, recognising that there may be other psychological, social and physical factors at play.

What is psychological formulation?

There is no universal definition of formulation, and it is understood and used in different ways by different groups. In psychological therapies, however, it might be seen as a “puzzle” on which the therapist and client must work to understand how a difficulty has developed, why it is still present and what can be done to help alleviate its effects.

Constructing meaning out of mental distress has a very long history. For example, Freud wrote:

I was trained to employ local diagnoses... and it still strikes me myself as strange that the case histories I write should read like short stories and that, as one might say, they lack the serious imprint of science... Case histories of this kind... have, however, one advantage... namely an intimate connection between the story of the patient's sufferings and the symptoms of his illness.



Further reading

- British Psychological Society: Good Practice in Psychological Formulation can be accessed at:

→ <http://www.canterbury.ac.uk/social-applied-sciences/ASPD/documents/DCPGuidelinesforformulation2011.pdf>

Unit 4. Psychological support for people with learning disabilities

While different models of formulation exist, there are several essential features of formulations across different therapeutic modalities. All formulations:

- summarise the client's core problems
- suggest how the client's difficulties may relate by drawing on psychological theories and principles
- aim to explain, on the basis of psychological theory, the development and maintenance of the client's difficulties at this time and in these situations
- indicate a plan of intervention based in the psychological processes and principles already identified
- are open to revision and re-formulation.

Psychological formulation is the process of gathering information from an assessment and using it to make sense of the person's psychological difficulties. Formulation is not simply a case of listing the factors: it is a process of considering how the factors contribute to the problem with which the person presents.

A formulation will help the clinician, the client and other people involved in his or her life understand what the issues are and why they might have happened, helping to answer the questions "Why me?", "Why this problem?", and "Why now?"

A comprehensive psychological formulation is particularly important when working with people with learning disabilities. As we've discussed in Units 2 and 3, people with learning disabilities can be among the most complex client groups to work with. Psychological formulations may need to take account of lots of information about the person, including his or her:

- communication skills
- level of ability
- life experiences, such as living in a long-stay hospital or experience of bereavement
- mental health
- sensory issues
- physical and neurological issues
- home and community placements
- relationships
- relationships with staff
- meaningful activities
- quality of life
- autonomy and choice
- financial resources
- support from organisations' practices and philosophy
- experiences of stigma and discrimination in the community.

Unit 4. Psychological support for people with learning disabilities

Many people and sources of information may need to be consulted, such as:

- learning disability health staff
- general practitioner
- social worker/care manager
- care provider organisation
- day care provider (if different)
- family
- previous casenotes/reports.

Psychological formulation considers a range of causes for the development and maintenance of psychological difficulties. It can be seen to follow the **biopsychosocial model (BPS)** in taking account of numerous factors that could explain a person's current difficulties.



Key psychological concept

The biopsychosocial model

The biopsychosocial model (BPS) suggests biological (such as underlying genetics), psychological (thoughts and emotions) and social (socio-economic, socio-environmental and cultural) factors play a significant role in the development of illness. It suggests that health is best understood in terms of a combination of biological, psychological and social factors rather than purely in biological terms.



Further reading

- A brief summary of the biopsychosocial model can be found at:
→ http://nursingplanet.com/theory/biopsychosocial_model.html

Frameworks for formulation: the 5 Ps model

As we noted earlier, there are many different sources from which information should be gathered. A model or framework is used to make sense of the information.

Various formulation models exist, but the most commonly used is known as the "5 Ps" (Figure 4.1)

The 5 Ps consists of the following:

- identification of the **p**roblem
- why the person may have been predisposed to these difficulties (**p**redisposing factors)
- why the problem arose now (**p**recipitating factors)
- what keeps the problem going (**p**erpetuating factors)
- what positive factors may be helpful for the person at present and in the future to help him or her avoid difficulties of a similar type (**p**rotective factors).

Unit 4. Psychological support for people with learning disabilities

An example of formulation

The following provides an example of how formulation (with the 5 Ps model) might be used to explain a person's difficulties. In this case, we'll be talking about someone called **John**.

John is a 56-year-old man with a mild learning disability. He reports that he has always been a “worrier”. His father died after a long illness when John was young. John became ill with stomach pains around five years ago. Although these resolved, the cause of the pains was never established. Since then, John has become increasingly anxious, to the point that he often refuses to leave his home for days at a time. When he leaves home, he often experiences “panic” (where he feels his heart beating very fast and he can't breathe) and asks his support worker to take him home.

At home, he spends a lot of time watching the news and tends to focus on stories that involve health “scares”, such as ‘flu epidemics or hospital ward closures.

John has very good relationships with his support workers, all of whom say they enjoy working with him. He also has a number of friends in the local area who come to visit him, although his increasing difficulties are gradually affecting his relationships.

If you were to formulate John's case, you might use the 5 Ps model to structure the information we have about John in this way:

- **p**roblem: anxiety at leaving home and panic attacks when out
- **p**redisposing factors: illness of father when John was young
- **p**recipitating factors: unexplained illness with stomach pains

- **p**erpetuating factors: John will leave the house but often returns immediately on experiencing a “panic”, “reinforcing” his anxiety; he continues to watch stories about illness on the television and has never had an explanation for his stomach pains
- **p**rotective factors: good relationships with support staff and continuing contact with friends.

A formulation, however, is not simply a case of listing factors. It is also important to specify how these factors **interact** with each other and lead to the person's current difficulties.

In John's case, we might say that the **illness and death of his father** when John was young may have led him to become very **aware of health issues**. When he experienced a **problem with his stomach**, and a cause for this was never found, John's **anxiety about health may have been heightened**. At that point, he may have begun to **monitor his own physical sensations**, looking for any signs of illness. Later, this may have made him **more susceptible to panic attacks**, since these often occur when people become very aware of their physical sensations and “panic” that they signal something is seriously wrong.

John's difficulties with anxiety may have become entrenched because he **continues to watch news stories about health scares**, which often do not present balanced accounts. John will also return to his house when he becomes anxious, so he does **not have an opportunity to “learn” that his anxiety will subside** if he stays outside for long enough.

On a positive note, **John's staff team and friends appear to be supportive**, and this might be one means of facilitating John to leave his house, possibly to attend pre-planned activities.

Unit 4. Psychological support for people with learning disabilities

As you can see, a formulation becomes a “story” that suggests how a person’s difficulties may have developed and persisted. **The story does not have to be “right” to start with:** it is often a series of “hypotheses”. Formulations will change over time if more information becomes available, or if treatments guided by the formulation are not successful.



Learning activity 4.5

- **Either by yourself, or with your mentor, consider whether you have used formulation in your current or past jobs.**
- **If you have, how have you used it, and how has it helped you understand others’ difficulties?**
- **Has it helped you take a particular approach to helping/supporting an individual and, if so, what has it helped you to do?**
- **How could you incorporate formulation more into the work you do?**



Learning activity 4.6

Case study: Robert

Robert has had to go for an assessment of his health needs because of changes to the benefits he receives. When he arrives for his assessment, he is asked a lot of questions he doesn’t understand. He tries to tell the assessor about his problems as this seems to be what the assessor is asking about.

He describes an incident that happened at school when he was 12. One of the older boys had taken Robert into the toilet. The older boy had made Robert touch his penis and forced Robert to put his penis in his mouth. The older boy then told Robert that if he told anyone about this, he would “kill him”. Robert was very scared and promised not to tell. This is the first time he has ever said anything about it.

Robert then tells the assessor he got into trouble for touching boys and girls when he was at school and that a policeman visited him at home and told him if he did it again, he would go to jail.

Recently, Robert saw a boy he was at school with – not the person who had abused him, but another boy. This had set him thinking about school and the abuse he experienced. He began to feel sad and found himself crying more and more.

Robert can get very angry at times. He has hit his sister on a number of occasions and falls out with her all the time. He knows it’s not OK to do this but sometimes feels like he can’t help himself. His sister has a lot of friends and goes out clubbing every weekend.

Unit 4. Psychological support for people with learning disabilities

Learning activity 4.6 (continued)

She has a part-time job and is going to college. Robert gets very jealous of her, even though she's mostly pretty nice to him.

Robert doesn't have a job and doesn't have many friends. He spends most of his time in the house, watching TV and eating. He's quite overweight. He doesn't go out much because many local people verbally abuse him.

After talking about all these things, Robert gets very upset and starts crying. The assessor can't get him to say anything else and Robert continues crying for the remainder of the assessment.

The assessor, who has some background training in psychology, thinks that Robert may be experiencing some issues with his mental health. She checks with Robert if she can call his GP and talk to him about the things Robert has spoken about. Robert agrees to this and to making an appointment with his doctor to discuss the issues.

Think about the 5 Ps model of formulation. Try to identify the factors that would be placed in each of the 5 Ps of the model if you were working with Robert. You can draw out different boxes for each "P". You might find you have more information for some factors than for others.

Once you've done this, complete the following task.

- Consider how the factors you've identified might interact with each other to lead to Robert's current difficulties.
- What other information would you want to help to improve your formulation?
- Who might Robert go to for further help after he has seen his GP?

Using formulation when working with teams

The process of formulation using a model such as the 5 Ps is an important means of understanding how multiple factors (including people involved with the person) may have resulted in current difficulties.

Formulation will help to clarify the questions: "What is the problem?"; and: "Whose problem is this?" It is essential to specify what the problem is, as there can be variation in reporting between the client and carer and among carers, who may have different tolerances or attitudes and may hold very different views about what constitutes a problem. Additionally, people with a learning disability may not understand or accept that what they are doing presents difficulties to themselves or others, and may report that they do not have any problems.

Sharing formulations, either verbally or in writing, can be very helpful but must be done with sensitivity. This is particularly important when the information gathered in the assessment suggests that the behaviour of others, such as family members or paid carers, may be contributing to the problem. Although therapeutic relationships are usually formed with the client in psychological therapy, a therapeutic alliance is often also formed with family and paid carers.

Clearly, the process of sharing a formulation requires a client's consent, if he or she has capacity in this respect. It may not be appropriate to share the materials used to develop the shared formulation, but an amended formulation for family and/or professionals can be developed. This should include the same essential elements as a shared client formulation, but the language may be altered.

Unit 4. Psychological support for people with learning disabilities

Sharing a formulation with a person with a learning disability

Individuals are more likely to adhere to treatments offered when they understand their difficulties through a shared formulation. Their sense of control and self-determination is also likely to increase.

The process of sharing a formulation may be even more important for people with learning disabilities, who may not have had the opportunity to speak about their difficulties with someone in a structured way or thought through their current difficulties and come to an understanding. Developing a shared formulation can therefore be just as important as any psychological therapy that follows.



Learning activity 4.7

Case study: Robert

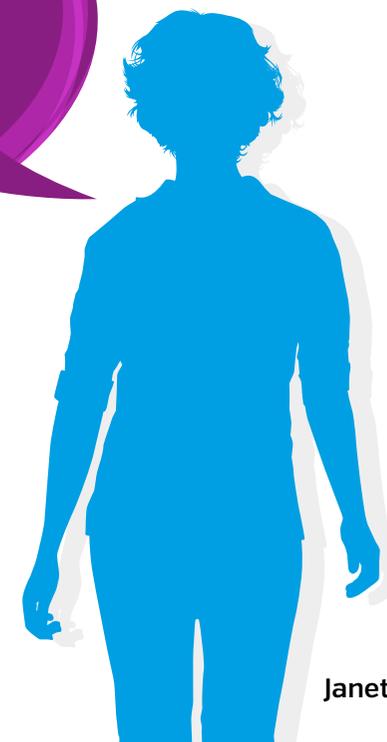
Either by yourself, or with your mentor:

- write down what you think the essential considerations would be when sharing a formulation with Robert.

Section 3.

Psychological therapies for people with learning disabilities

“ Because someone was listening to what I was talking about I am beginning to go out now. They listened to me without interruption. I’m moving onto new things. It has helped me to feel more confident. I do not hide or feel frightened. ”



Janet

Unit 4. Psychological support for people with learning disabilities



Learning outcomes

By completing this section, you will:

- discuss the development of psychological therapies for people with learning disabilities
- reflect on how psychological therapies might be used when working with a person with a learning disability
- identify potential issues in developing a therapeutic relationship with a person with a learning disability
- identify the main aspects of the stepped-care model of psychological therapies and how this might be applied when working with a person with a learning disability
- identify when you can support an individual and when referral to other professionals is necessary
- name the main types of psychological therapy used with people with learning disabilities
- understand and reflect on the importance of supervision for those providing psychological therapies.

As we noted in Unit 1, the levels of competency required to deliver psychological therapies within a **stepped-care model** will vary depending on the therapy and client group. Adaptations to therapies may be necessary in learning disability, so supervision by, and guidance from, experienced practitioners in the field is of particular importance. But an understanding of the nature and role of therapies will be helpful even for staff who are not delivering psychological therapies directly by enabling them to identify when an assessment of psychological needs is merited.

Psychological interventions for people with learning disabilities: past history and current views

It was long assumed that people with learning disabilities would be unable to benefit from a “talking therapy” (such as cognitive behavioural therapy) in the belief that someone with a learning disability would not have sufficient insight into his or her own thoughts and feelings to be able to manage. The term **“therapeutic disdain”** was coined to describe this standpoint. “Behavioural” approaches using theories of learning and skills-training or pharmacological interventions were commonly adopted instead.

We now recognise that some of the therapies used to assist people without learning disabilities can also be helpful for people with learning disabilities. Efforts put into supporting clients to develop “emotional vocabulary” and insight into their own cognitive processes can allow individuals to benefit from interventions.

The **behavioural approach** is still the most likely intervention to be used with people with severe disabilities whose behaviour presents significant challenges to services. Such individuals may be unable to sit down and talk to a therapist, so much of the information for a formulation is gleaned from observation and talking to family and paid carers. As much as possible will

Unit 4. Psychological support for people with learning disabilities

be done to try and engage the person in the process and ensure that what is being done is not aversive to them.

While it might not be possible to share thoughts about formulation with the person, developing a shared formulation with family and paid carers is an essential part of the therapeutic process. It is likely that the therapist will expect the family and paid carers to be involved in any intervention; they need to be able to understand and agree with the formulation and proposed intervention.



Further reading

- Brown, M, Duff, H, Karatzias, T. & Horsburgh, D. [2011]. A review of the literature relating to psychological interventions and people with intellectual disabilities: Issues for research, policy, education and clinical practice. *Journal of Intellectual Disabilities*, 15, 31–45.

Who can be a therapist?

NHS Education for Scotland (NES) has been working in partnership with the UK-wide organisation Skills for Health, the National Institute for Mental Health in England (NIMHE) and the Care Services Improvement Partnership (CISP) to describe the competences necessary to deliver psychological therapies and supervise others who are in training or delivering within the service. All NHS Boards are currently being encouraged to review their service provision, staff training and supervision arrangements in the light of these developments.

The stepped-care model

Stepped care is a tiered approach to service provision, with high-volume, low-intensity interventions being provided to patients with the least severe difficulties. Subsequent “steps” are usually defined by increasing levels of case complexity and intensive forms of treatment. The model aims to ensure that clients receive treatment at an intensity that is appropriate to the presenting problem (see Box 4.3) and with appropriate clinical supervision.

Box 4.3. Levels of service delivery

According to the Scottish Government, most service-level based psychological therapy models should have levels of service delivery corresponding to the following.

Low-intensity interventions

Protocol-driven interventions aimed at less complex mental health illnesses and disorders and normally lasting between two and six sessions.

High-intensity interventions

Traditional standardised psychological therapies (such as Cognitive Behaviour Therapy, Interpersonal Psychotherapy, short-term focused Psychodynamic Psychotherapy) aimed at moderate-to-severe mental illness and disorder with significant complexity, sometimes within a specialist service and normally lasting between six to 20 sessions.

High-intensity specialist interventions

Individually tailored interventions based on case formulations drawn from a range of psychological models, aimed at service users with highly complex and/or enduring mental illness or disorder and normally lasting 16 sessions or more.

Unit 4. Psychological support for people with learning disabilities

The Scottish Government published the first edition of the Psychological Therapies Matrix in 2008, with a further update published in 2011. The Matrix aims to provide guidance on evidence-based psychological interventions in key priority areas.



Further reading

- NHS Education for Scotland (NES) has developed guidance and training in relation to delivery of psychological therapies. Details of this can be found on the NES website:
 - <http://www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/training-psychologists/clinical-supervision/nes-training-in-generic-supervision-competences-for-psychological-therapies.aspx>
- You can access the Psychological Therapies Matrix at:
 - <http://www.nes.scot.nhs.uk/media/20137/Psychology%20Matrix%202013.pdf>



Learning activity 4.8

- Either by yourself, or with your mentor, write down what you know about the provision of psychological therapies within your service or area. You may need to consult with colleagues in other disciplines, particularly clinical psychology, to be able to answer this.
- What professions are involved in the delivery of therapies?
- What therapies are offered?
- What are the referral criteria for psychological therapies in your service/area?

Developing a therapeutic relationship

The therapeutic relationship is considered a fundamental aspect of psychological therapy. It has been broadly defined as the collaborative and effective bond between therapist and client. Research has shown that a good therapeutic relationship is strongly associated with positive outcomes from therapy, regardless of which therapeutic model is followed.

A limited amount of research exists on the role of the therapeutic relationship with people with learning disabilities, but its importance can be assumed. It is nevertheless possible that **the therapeutic relationship may be more complex when undertaking psychological therapy with a person with a learning disability than with someone without a disability** due to several factors:

Unit 4. Psychological support for people with learning disabilities

- clients may not know what to expect in therapy: they may not understand the role of the therapist, possibly thinking of him or her as a friend, particularly if they have not experienced having their difficulties being listened to for a long time
- there is often a power imbalance between therapist and client: this may be magnified by a number of factors in the case of psychological therapy with people with learning disabilities, including perceived differentials in status, ability and role
- the client is less likely to have self-referred, so may be less motivated to engage.

Therapists working with people with learning disabilities often have a dual role, working with clients but also with professionals and family or paid carers. This can bring tensions if others wish to be further involved but the client and therapist see the protection of confidentiality as being essential.

Why am I seeing you anyway? Clients' understanding of psychological therapy

“ They'll want to know what's been wrong with me all my life. I might tell some of it. ”
Kilbane & Jahoda, 2011

People's expectations prior to therapy is a key factor in determining outcomes. This includes:

- whether clients believe the therapy will work
- what they think they will do
- what they think the therapist will do.

There is very little research on these factors for people with learning disabilities. What research there is suggests that people may know the function of therapies offered by clinical psychologists (to help them with their difficulties), expect it to help them and that it will end after a period of time, albeit lengthy. There is less understanding, however, of the need for therapy to be collaborative (between the client and therapist): the expectation is that the therapist will instruct the client on what actions to take to alleviate difficulties.

One possible explanation for this is that people do not know what psychological therapists (in this case, clinical psychologists) do. One study found that the role of a psychologist had not been explained to half of the clients who were referred to a clinical psychology service. An even higher percentage were unaware that a referral to clinical psychology had been made in the first place.

Unit 4. Psychological support for people with learning disabilities



Learning activity 4.9

Case study: Robert

Robert's GP referred him to the local community learning disabilities team. Robert gets a letter saying that a community nurse is coming to visit him. The letter doesn't say why.

When the community nurse arrives, he asks Robert a lot of questions. They range from how much he eats, to has he hit anyone over the last week? After over an hour, Robert is a bit tired and confused. He can't really remember a lot about what the nurse said, except that someone else is going to see him. He's not very sure what they're going to see him for, as he can't remember exactly what the nurse told him.

Robert gets another letter saying a psychologist wants to see him. He has to go to the hospital to see this person and has to wait in two different waiting rooms for nearly 20 minutes.

A man called Dr Balfour comes and gets him from the waiting room. They go into a room where Dr Balfour sits behind a big desk. The room has a bed and curtains in it and some other bits of machinery that Robert isn't very sure about. He's also not very sure what Dr Balfour is going to ask him to do.

Dr Balfour starts to ask lots of questions, like the nurse did, and Robert is struggling to answer them. Robert finds he can't speak. He's a bit scared of, and angry at, Dr Balfour and starts to cry. He can't stop himself.

Dr Balfour tries to comfort him, but Robert tells him to go away. Dr Balfour tells Robert he's going out to get some water for him and he'll be back in a minute. He gets the water and brings Robert a TV magazine to have a look at because he said he likes watching TV. Dr Balfour asks Robert about his favourite TV programmes. Robert shows him some of them in the magazine and they start talking about some of the people in the TV shows he likes.

Soon Robert feels a bit less scared and angry. Dr Balfour tells Robert to call him Stephen. He comes round from behind his desk and talks more to Robert. Stephen brings out some pictures and asks him how he thinks the people in the pictures are feeling. He asks him about how he feels and uses other pictures to help show him things that are happening to him.

After they are finished, Stephen tells Robert he wants to meet him again to find out more. Between them, they'll try and work out what might be happening to Robert and what they can do to help him feel more like going to the pub again.

Either by yourself, or with your mentor, consider the case study above.

- **List all the factors/events that might have prevented Robert from engaging in therapy.**
- **List all the factors/events that might have encouraged Robert to participate in therapy.**

Unit 4. Psychological support for people with learning disabilities



Further reading

- Kilbane, A.L. & Jahoda, A. [2011]. Therapy expectations: preliminary exploration and measurement in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24, 528–542.
- Willner, P. [2003]. Assessing prior consent: An audit of referrals into a clinical psychology service for people with learning disabilities. *Clinical Psychology*, 30, 25–28.



Learning activity 4.10

Case study: Christina

Christina's workers have noticed that her behaviour has dramatically deteriorated. She is constantly hoarding food, and the workers have had to call in pest control to deal with mice because of this.

Her sleep pattern is very poor, with neighbours reporting that they have seen her wandering along the street in her nightclothes. The police picked her up on one occasion and social work had to be involved.

Christina is now incontinent on a daily basis. She has had a number of physical checks but no underlying cause could be found, and no attempt has been made to try to support her with her incontinence. Pads are being used and Christina's sister is concerned that this will lead to her being excluded from some activities, like swimming, which she previously enjoyed.

A case conference was called. It emerged that most of the difficulties had started when Christina went to her exercise class. The manager of the provider organisation mentioned that she had met someone she'd known in hospital there and they had been trying to support her to stay in the group as she seemed to like it. When the manager revealed the name of the other service user, Christina's sister, who had come up from England for the meeting, said: "Not her – she made Christina's life a misery!"

Unit 4. Psychological support for people with learning disabilities

Learning activity 4.10 (continued)

As the case conference progressed, it became clear that many of Christina's difficulties could be emotional and psychological. One of the action points from the meeting was that she would be referred to the community learning disabilities team for psychological assessment and intervention.

The social worker completes the referral and the psychologist arranges to see Christina at home. When he arrives, Christina gets very upset, starts pacing around the living room and eventually tells the psychologist to leave, adding: "Nobody comes into my house and tells me what to do."

The psychologist contacts the social worker and care staff. It appears that no-one has explained the referral to Christina or checked it was something she would want.

They agree that the psychologist will meet with the workers first and get some information from them. The workers would then facilitate a meeting between Christina and the psychologist.

When the psychologist meets with the workers, he tells them about the referral from the social worker, which reads: "Behaviour change noted, which could be psychological, but some concerns raised that Christina may be experiencing the early stages of a dementing illness".

Staff say they are not aware of any suggestion of dementia, and that they have been under the impression the things happening to Christina were emotional and behavioural in origin. The workers are quite angry about this, some believing that information has been withheld from them and others that the information is simply untrue. "Social work are just trying to get her into a care home because of the night-time problems," one says.

Consider, either by yourself or with your mentor, the following questions.

- **What factors have hampered the development of the therapeutic relationship – with Christina and with the workers?**
- **How would you deal with the workers' anger, and what action would you take to try to resolve the situation?**
- **If you were asked to do this over again, detail, step-by-step, how you would support Christina through the referral process. Would you do anything differently with staff?**
- **What other things do you think might be affecting Christina (think of age and stage and some of the presenting problems)?**

Unit 4. Psychological support for people with learning disabilities

Psychological therapies

Numerous psychological therapies are available, although most fall into three distinct categories: **cognitive**, **behavioural** and **psychodynamic**. These come from the theories of behaviour that we describe in the Key Psychological Concept box opposite.

The UK Council for Psychotherapy provides definitions for most psychological therapies, along with details of governing bodies and training requirements. Descriptions of all of these therapies are beyond the scope of this resource, but we will focus on the most well-known and widely used.



Further reading

UK Council for Psychotherapy:

→ <http://www.psychotherapy.org.uk>



Key psychological concept

Psychological theories of behaviour

Generally, psychological theories attempt to explain why people think, feel and act in particular ways. From the myriad of psychological theories, three main overarching theories are considered the foundation of the various psychological therapies typically used in the NHS.

Behavioural theories

These focus on the study of behaviour that can be directly observed. Much of behavioural theory is concerned with how humans and animals learn how to act. They commonly underpin clinical interventions aimed at reducing the impact of challenging behaviour.

Cognitive theories

Cognitive theories describe how aspects of thinking and information-processing can impact on learning, emotional expression and behaviour. They have driven the development of cognitive therapies, which have been among the predominant therapeutic approaches in recent years.

Psychodynamic theory

Often known as “Freudian theory”, psychodynamic theory encompasses a theory of development and personality and proposes factors that may influence the development of abnormal functioning or behaviour. Psychodynamic psychotherapy is based on Freudian theory, although it has been developed and refined over time by a number of prominent theorists and therapists.

Unit 4. Psychological support for people with learning disabilities

Key psychological concept: Psychological theories (continued)

Many psychological theories appear helpful in explaining some aspects of learning or behaviour and the development of mental health difficulties. None, however, can adequately explain all aspects of human experience.

Medical and social models are also helpful in explaining some elements of the development of mental illness. In more recent years, the amalgamation of psychological, social and medical theories into biopsychosocial models has provided a more useful basis for the formulation of psychological or behavioural difficulties.

Cognitive therapies

Cognitive Behaviour Therapy

Cognitive Behaviour Therapy (CBT) aims to help a client gain insight into the way he or she thinks (cognition) and acts (behaviour) and an understanding of the influence of emotions. The focus of CBT is on the “here and now”, although past experiences, such as childhood trauma, may form part of the “explanation” for a person thinking and behaving in a certain manner when developing a formulation.

CBT has been used to treat conditions such as depression, anxiety, eating disorders and abuse. Much research into the effectiveness of CBT in the general population has been carried out. While the evidence base for people with learning disabilities is more limited, recent studies have shown that CBT can be effective for a range of difficulties they experience, including anger,

depression and anxiety. This is despite doubts over CBT’s appropriateness in learning disabilities due to its reliance on verbal skills, the ability to report thoughts and feelings, to weigh evidence and to engage in a range of abstract thinking skills.

Cognitive Analytic Therapy

Cognitive Analytic Therapy (CAT) is described as a “collaborative programme for looking at the way a person thinks, feels and acts, and the events and relationships that underlie these experiences (often from childhood or earlier in life).” It is designed to bring together aspects of cognitive psychotherapies (such as CBT) and psychoanalytic approaches into one integrated therapy.

CAT practitioners claim that its relational approach means it does not need to rely on a relatively high level of verbal ability or psychological mindedness, which some people with learning disabilities can find difficult. Instead, CAT aims to pay attention to “where the client is at in their emotional, functional, and relational approach to life as well as their place in wider society”. It can be particularly helpful for people with learning disabilities owing to its clear processes and structure, especially its time-limited nature and focus on endings, all of which can be clearly described.

It is recommended that some changes are made to the CAT process when working with people with learning disabilities, such as:

- using accessible and adapted tools, drawings and audio-taped prose letters
- extending the assessment period
- slowing down the pace of therapy.

Unit 4. Psychological support for people with learning disabilities

Some developments in the CAT model are more central, such as using its systemic approaches to work with staff teams, especially those who work with people with challenging behaviour.

The body of evidence of CAT's effectiveness for people with learning disabilities and their carers is growing.



Further reading

- The British Association for Behavioural and Cognitive Psychotherapies (BABCP):
→ <http://www.babcp.com>
- The Association for Cognitive Analytic Therapy (ACAT):
→ <http://www.acat.me.uk>
- ACAT DVD:
→ <http://www.acat.me.uk/page/dvd+about+cat>

Necessary skills for cognitive therapy

Necessary skills include the ability to:

- identify and “label” emotions
- link emotions to situations
- select an emotion, given a situation and a belief
- select a belief, given a situation and emotion.

People with learning disabilities may struggle with some aspects of this [particularly understanding the links between emotions and beliefs], but evidence is now emerging that training in understanding these links can significantly improve the ability of individuals with learning disabilities to engage in the process and develop the necessary skills to benefit. Many may not have had the opportunity to work in this way before, so skill-building in advance of direct therapy can be valuable. Adapting psychological therapies for people with learning disabilities is discussed below.



Further reading

- Bruce M., Collins S., Langdon P., Powlitch S. & Reynolds S. (2010) Does training improve understanding of core concepts in cognitive behaviour therapy by people with intellectual disabilities? A randomised experiment. *British Journal of Clinical Psychology*, 49, 1–13.

Unit 4. Psychological support for people with learning disabilities

Psychodynamic psychotherapy

Psychodynamic psychotherapy encompasses a number of types of therapy, all with the common ground that they focus on past experiences and beliefs [of which the person may not even be aware] to understand current relationships and behaviour.

The client is encouraged to talk about his or her early life experiences and relationships and links are made with how the person's expectations of relationships have been coloured. Psychodynamic psychotherapists use techniques such as free-association [inviting the client to say whatever is in his or her mind] and monitoring what the client does not say in words but may be hinting at in behaviour or tone of voice. The therapist will be seeking to interpret how the client's current difficulties may be influenced by these conscious and unconscious responses in his or her relationships with others throughout the process.

Use is relatively limited within the learning disability field, although research suggests that it may be of benefit to some clients. Difficulties in verbal communication and the abstract nature of some of the concepts within the model are likely to have contributed to its limited use with all but the most able of clients. Research into promoting developments to increase its availability to clients with learning disabilities is nevertheless ongoing.

Positive Behaviour Support

Positive Behaviour Support is an approach used for the management of challenging behaviour in people with learning disabilities. Behaviour can be described as challenging when it is “of such an 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” [BPS/ RCP/RCSLT, 2007].

Typically, the intervention involves assessment to identify factors that trigger and perpetuate the challenging behaviour. Steps are then taken to reduce the triggers or maintaining factors and their impact on the individual. This type of work commonly requires a systemic approach, with carers being asked to alter:

- their method or style of communication with the individual
- some aspect of the individual's environment (such as noise level or choice of activities)
- the way in which they respond to episodes of challenging behaviour.

It's crucial to acknowledge that carer responses to challenging behaviour may be influenced by factors over and above their knowledge and skills in the management of such behaviour. Research has increasingly focused on the influence of cognitive and emotional factors (such as the feelings evoked) and beliefs about the origins and controllability of the behaviour on carer responses and, in turn, the success of behavioural interventions.

Applied Behaviour Analysis [ABA] is similar to PBS – indeed, the approaches are often considered identical, but some differences exist. A discussion of this can be found in the Johnston et al. [2006] reference in “Further reading”.

Unit 4. Psychological support for people with learning disabilities



Further reading

- NHS Education for Scotland has produced a training programme on Positive Behaviour Support aimed at trained staff working with clients with challenging behaviour. Details of this programme can be found on the NES website at:
→ http://www.nes.scot.nhs.uk/media/570730/pbs_interactive_final_nov_12.pdf
- Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists. [2007]. Challenging Behaviour: a unified approach. London: BPS.
- Johnston, J.M., Foxx, R.M., Jacobson, J.W., Green, G. & Mulick, J.A. [2006]. Positive behavior support and applied behavior analysis. *The Behavior Analyst*, 29, 51–74.

Behavioural Family Therapy

Behavioural Family Therapy (BFT) is particularly well embedded in learning disability services in the UK and abroad.

As we discussed in Unit 3, many people with learning disabilities live with a family or receive support from paid carers. There can be considerable stress within some of these homes, leading to problems with communication and disagreements on solving day-to-day problems and setting future goals for the person and family.

BFT is about consolidating and developing communication and problem-solving skills and does not seek to “blame” any individual. It does not specifically address a particular mental health issue or problem area, but can impact on interactions that may be maintaining some of the difficulties.

BFT should be considered when a person with a learning disability has a defined mental health problem, behavioural issue or other difficulty for which stress within the family/carer unit is a maintaining factor.

Art Therapy and Music Therapy

These use the processes of art and music to develop a therapeutic relationship with individuals, often those with learning disabilities or mental illness who have communication difficulties that restrict access to psychotherapeutic interventions.

The rationale is not to produce pieces of art or music, but to offer a means of developing a therapeutic relationship with a client in a non-threatening way. The focus can be on the piece of art being created by the client, rather than direct one-to-one communication.



Further reading

- Details of Art Therapy can be found through the British Association of Art Therapists: → http://www.baat.org/art_therapy.html
- Details of Music Therapy can be found through the British Association for Music Therapy: → <http://www.bamt.org/>

Unit 4. Psychological support for people with learning disabilities

Adapting psychological therapies for people with learning disabilities

“Talking therapies” have become more widespread with people with learning disabilities, but “manualised” therapies (in which the therapist must follow a pre-defined programme) that are not specifically developed for clients with learning disabilities can be particularly problematic. Adaptations can nevertheless be made to therapeutic techniques to support people with learning disabilities to access these therapies.

Recommended adaptations include:

- **simplification:** using more straightforward techniques, explaining the process more, reducing the length of sessions
- **language:** simplifying speech, using shorter sentences and more easily understood words
- **activities:** using drawings and homework assignments to help the client understand and remember the work from sessions
- **developmental level:** considering the person’s developmental level and using appropriate games, discussion of current news stories or television programmes to support therapeutic techniques
- **directive methods:** being more directive (depending on the person’s ability level), perhaps defining treatment goals and using visual materials to highlight progress
- **flexible methods:** adjusting techniques to suit the client’s ability level
- **caregiver involvement:** involving family or support staff is more common with clients with learning disabilities, with consideration being given to confidentiality issues, blurring of roles for support staff and the risk that the client will not feel in control of his or her own treatment

- **transference:** recognizing that the client may [unconsciously] transfer some of his or her feelings about relationships with a parent onto the therapist by, for instance, being “childish” or angered if asked to undertake a task between sessions
- **disability/rehabilitation approaches:** addressing the issue of disability within the treatment, with the therapist supporting the client to develop a positive view of him or herself.



Further reading

- Hurley A., Tomasulo D. J. & Pfadt A. G. [1998]. Individual and group psychotherapy approaches for persons with intellectual disabilities and developmental disabilities. *Journal of Developmental and Physical Disabilities*, 10, 365–386.
- Stenfert-Kroese, B., Dagnan, D. Loumidis, K. [1997]. *Cognitive-Behaviour Therapy for People with Learning Disabilities*. London: Routledge.

Child CBT resources, such as the “Huge Bag of Worries” or “Think Good Feel Good”, can be helpful in working with clients, but it’s important to ensure that the material used is age-appropriate and the client does not find the approach patronising. The key to the effectiveness of all psychological therapies is to ensure that formulation and intervention are **meaningful** to the person.

Therapists should be flexible and willing to adapt their work to fit with the needs of the client. Use of good communication techniques, as we discussed in Unit 2, should be the cornerstone, with the therapist checking whether the client has understood the work completed so far.

Unit 4. Psychological support for people with learning disabilities

The issue of **generalisation** of skills (such as anger management skills) the person has learnt during therapy to everyday life often arises when working with people with learning disabilities. Involving support staff or family members to support the person to practice new skills between sessions (and following the end of therapy) is helpful, taking care to observe confidentiality rules, avoid the risk of the client becoming “dependent” on a certain member of staff and recognise the effects of a potential “blurring” of boundaries between direct support and therapeutic input.



Learning activity 4.11

Case study: Michael

After attending the meeting at the centre, Michael's parents are becoming increasingly concerned about his behaviour. He continues to shout and scream and his sleep pattern is worsening. Mum continues to believe he is intentionally trying to kick out at people and one of the workers at the centre agrees.

The situation is discussed with Michael's key worker at the centre and it is agreed that a referral will be made to the community learning disabilities team.

Michael's family and the day centre are visited by three members of the team: a community nurse, clinical psychologist and speech and language therapist. They explain that they will carry out an assessment of the different areas of Michael's life and generally use a Positive Behavioural Support framework when assessing and intervening with people who are experiencing similar difficulties to Michael.

Either by yourself, or with your mentor, consider the following.

- **What steps do you think the team will go through to complete the assessment?**
- **What information are they trying to collect?**
- **What will they do with the information once they've got what they need?**

Unit 4. Psychological support for people with learning disabilities



Learning activity 4.12

Case study: Patricia

Patricia is a 28-year-old woman with a learning disability. She lives with her mum and dad in a fairly chaotic family household. At any time, between one and three of her five siblings can also be living at home, depending on issues within their own relationships, employment status and finances.

Understandably, with anything up to six adults living in the house, disagreements and difficulties can arise between family members.

Patricia presents with low mood, anger and can be aggressive at times. The family have reported that her aggression has increased of late and mum is struggling to cope. Patricia tends to shout and swear at family members and hits out at them at times. She can also spit at them, which is particularly difficult for the family.

The community learning disability nurse has recently visited Patricia's home to assess the situation, gathering the following information.

“Patricia currently is at home most of the time. Her aggression has led her to being excluded from some of the activities in which she previously participated. She is aggressive towards members of her family, hitting and spitting at them, can shout for long periods of time, and is described by her father as ‘very in your face’ and ‘difficult to get away from’.

“Patricia loves music. Her favourite singer is Daniel O’Donnell and her favourite band is One Direction. She has been to concerts featuring both, thoroughly enjoying them. She can amuse herself ‘for hours’, according to her mother, with her One Direction and Daniel O’Donnell DVDs and CDs.

“Patricia is viewed by family members as ‘manipulative’: they say she only behaves like this to get her own way.”

Patricia speaks to the nurse and says she is very unhappy now her brother is back home. She says he gets drunk a lot and that he used to hit her when drunk when she was younger. He doesn't do this anymore, but she is still a bit scared of him. She nevertheless tells the nurse that she can “give as good as I get now!”

Patricia is very angry at her family because she thinks they don't appreciate the difficulties she experiences; she feels she is always treated “like a we'an”. She wants more time away, but describes “a cloud in her head” when she gets angry and she hits out before realising what she's doing.

The family don't seem to communicate well with each other and the nurse notes that for much of her assessment, she feels like she's “refereeing”.

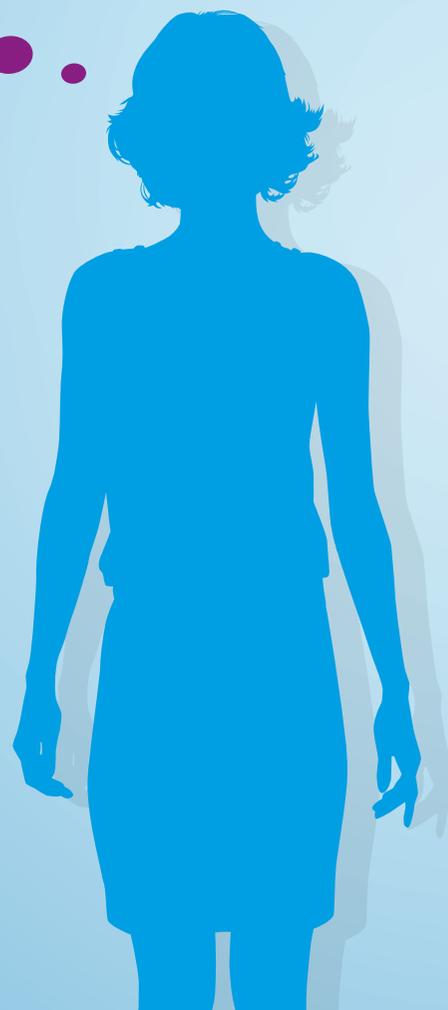
All family members appear stressed and irritable.

Either by yourself, or with your mentor, complete the following.

- **Use the 5 Ps formulation template (Figure 4.1) to identify factors that might explain Patricia's current presentation.**
- **Suggest materials that might be used to support the development of a shared formulation with Patricia.**
- **What amendments might be made when developing a shared formulation with Patricia's family?**
- **What difficulties might you foresee in the process of developing the formulation and sharing with Patricia's family?**
- **How would you overcome these?**



me...



Unit 5

Physical health

and psychological

well-being

Unit 5. Physical health and psychological well-being

Section 1.

Psychological effects of physical health on people with learning disabilities



Learning outcomes

By completing this section, you will:

- discuss the effects of physical ill-health on the psychological well-being of people with learning disabilities
- discuss the psychological effects of some interventions for physical health on people with learning disabilities.

Physical health’s role in the psychological well-being of people with learning disabilities

The link between good physical health and psychological well-being is well established, with psychological factors playing a role in management of physical health conditions and vice versa. Awareness of this link is of particular importance, as people with learning disabilities are at increased risk of chronic health conditions such as epilepsy, obesity and cardiac disease.

Risk factors for poor physical health include:

- social circumstances, such as low incomes, poor housing and unemployment
- communication difficulties preventing access to health education materials
- deficiencies in access to, and quality of, healthcare services.

Physical activity and psychological well-being

The benefits of physical activity on psychological well-being have been recognised for many years, but research shows that many more people with learning disabilities do not participate in physical activity than is found in the general population. Although physical conditions can make it difficult for some people to participate in selected activities, the attitudes of those supporting people with learning disabilities may have an important role. Research has shown that:

- carers’ intentions to support activity predicts participation
- carers’ beliefs about health difficulties, incontinence, access to transport and finance and about the role of physical activity and choice for the person they support are important.

There may be a need to support carers to understand physical activity’s role in improving clients’ physical and mental health. Establishing carers’ beliefs about physical activity is the first step in this process.

Unit 5. Physical health and psychological well-being

Weight management

Obesity in people with learning disabilities (particularly those with mild-to-moderate learning disabilities) has been increasing over the past 20 years. Contributing factors include poor diet, lack of exercise and lack of social support.

Psychological factors such as **learned helplessness** can be particularly relevant. Overcoming barriers such as this may involve practical support and some specific psychological techniques, particularly **motivational interviewing**.



Further reading

Further information on motivational interviewing can be found at:

→ <http://motivationalinterview.org/index.html>

- **See also:** Treasure, J. (2004). Motivational interviewing. *Advances in Psychiatric Treatment*, 10, 331–337.

Adherence to medication/medical intervention

Adherence to medication within the general population is often relatively low, with people commonly stopping treatment without informing, or consulting with, health professionals. The therapeutic alliance formed between health professionals and clients is essential in supporting adherence to treatment regimes, with the client's feeling of control over the intervention being particularly important. The same applies to people with learning disabilities: good communication and supporting the client to feel he or she has some control is essential.



Further reading

- The NES resource, *Emotion Matters*: taking a holistic approach to helping people living with long term conditions, can be accessed at:
→ <http://www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/emotion-matters.aspx>
- NHS Lanarkshire has a range of accessible materials relating to physical health. These are freely available for use at:
→ <http://www.nhslanarkshire.org.uk/HealthyLiving/Pages/default.aspx>
- Kaufman, G. & Birks, Y. (2009). Strategies to improve patients' adherence to medication. *Nursing Standard*, 2009, 23(49), 51–57.

Unit 5. Physical health and psychological well-being



Learning activity 5.1

Case study: Robert

Robert is now aged 26 and continues to live with his parents. He has been unsuccessful in getting long-term employment and, although he has 10 hours of direct support each week, usually says that he wants to go for lunch or to a café with his support workers. His diet has been poor despite his parents' efforts and he has put on a significant amount of weight, to the point where he has been warned that he is at risk of developing type 2 diabetes. This doesn't seem to worry him – he says that it “really doesn't matter”.

Either by yourself, or with your mentor, consider the following questions.

- You have been asked to see Robert. What psychological factors could be contributing to his health difficulties? Use the 5Ps formulation diagram in Unit 4 (Figure 4.1) to assist you in this.
- How would you address these difficulties?

Section 2.

Neurological and genetic conditions and psychological well-being



Learning outcomes

By completing this section, you will be able to:

- discuss the effects of some neurological conditions on the psychological well-being of people with learning disabilities
- discuss the effects of some genetic conditions on the psychological well-being of people with learning disabilities.

Epilepsy

Epileptic seizures are sudden, brief, usually un-provoked episodes of abnormal brain activity that can result in disturbances of consciousness, behaviour, emotion, motor function or sensation.

Epilepsy is the most common serious neurological disorder affecting people with learning disabilities, with prevalence ranging from 20–40%, 30 times higher than the general population rate.

The majority of people without learning disabilities become seizure-free on anti-epileptic drug medication, but epilepsy in people with learning disabilities is more difficult to manage. It presents an increased risk of hospitalisation and failures of packages of care in the community.

Unit 5. Physical health and psychological well-being

Chronic epilepsy may be associated with:

- **psychiatric conditions:** depression and anxiety are related to fear of seizures and their impact on quality of life, and isolation due to other people being anxious about spending time with the person in case they have a seizure
- **behavioural difficulties:** the person may be less willing to attend social events
- **socio-economic difficulties:** finding and maintaining employment is challenging
- **carer stress:** there is particularly anxiety about the risk of harm from seizures.

These difficulties should be assessed separately to the seizures: different factors, particularly in behavioural problems, appear to contribute to their presentation. Interestingly, loss of consciousness in seizures may be protective of emotional well-being (possibly because of a positive effect of seizures on mood, individuals being unaware of the seizure or being too tired to show distress).

No specific scales measure quality-of-life issues in people with learning disabilities and epilepsy, but scales for children, adolescents and adults without learning disabilities exist. It may be helpful to consider using the questions from these to structure an assessment. There are also scales to measure quality of life for people with learning disabilities and challenging behaviour, such as the Maslow Assessment of Needs Scale – Learning Disability (MANS-LD). Again, questions from these scales may provide helpful insights into a person’s feelings about his or her life.



Further reading

- Townshend, K.H., Dorris, L, McEwan, M.J et al [2008]. Development and validation of a measure of the impact of epilepsy on a young person’s quality of life: Glasgow epilepsy outcome scale for young persons (GEOS-YP). *Epilepsy and Behaviour*, 12, 115–123.
- Skirrow, P. & Perry, E. [2009]. *The Maslow Assessment of Needs Scale – Learning Disability*. Liverpool: Mersey Care NHS Trust.

Non-epileptic seizures

Non-epileptic seizures can have a number of different causes, but not disrupted electrical activity in the brain. They are therefore different from epilepsy.

Non-epileptic seizures can be divided into two types: organic and psychogenic. **Organic** events have a physical cause (relating to the body) and include fainting (syncope) and seizures through metabolic causes (such as diabetes). **Psychogenic** have a psychological cause, emerging as a result of the impact of thoughts and feelings on the way the brain works. They include:

- **dissociative seizures:** the most common type of non-epileptic seizures, they are involuntary and the person has no control over them
- **panic attacks:** these can happen in frightening situations, when remembering previous frightening experiences or when a person anticipates an anxiety-provoking situation; the person may lose consciousness and may convulse
- **factitious seizures:** the person has some conscious control – an example is seizures forming part of Münchausen’s syndrome, a rare psychiatric condition in which a person is driven by a need to have medical investigations and treatments.

Unit 5. Physical health and psychological well-being

Non-epileptic seizures used to be called “pseudoseizures”, but we now refer to them as “dissociative seizures”. This is helpful, as it does not describe the seizures in terms of epilepsy and does not imply that the seizure is “deliberate”.

People with seizures [epileptic or non-epileptic] and those around them [such as family and carers] should be given opportunities to talk through their concerns about the condition and the effects it may have on their quality of life and future opportunities.



Learning activity 5.2

Case study: Michael

Michael has had seizures since he was very young, rarely during the day but continuing to occur 2–3 times a week at night. His parents have various technologies in place to alert them to any seizures and have an epilepsy care plan that sets out actions they have to take during seizure activity.

The community learning disabilities team had produced a Behavioural Support Plan to respond to Michael’s behaviour changes, part of which was to increase the number of enjoyable activities that he took part in each week. The programme appeared to be having a very positive effect on his mood.

While Michael’s behaviour had started to be more manageable and he seemed much happier, his parents’ recordings showed quite a marked increase in seizure activity. Night-time seizures had increased in frequency to once or twice a night, with an accompanying increase in seizure activity during the day.

His seizures are quite intense, but afterwards he often appears more content and happier. He can be a bit agitated before seizures, although this has not been reported to the same extent.

Mum thinks Michael’s seizures are different than before. She thinks they are not epileptic and that sometimes he “fakes it”. Staff and his dad believe Michael is not capable of this.

Either by yourself, or with your mentor, consider the following.

- **Using the 5 Ps formulation model, start to identify any factors that could explain the seizures.**
- **What further information would you require to make sense of Michael’s difficulties?**
- **What would you suggest Michael’s parents and staff do to try to help make sense of, and manage, his new seizure pattern?**

Dementia

The life expectancy of people with learning disabilities has increased dramatically since the mid-20th century, with that of individuals with a mild learning disability now being the same as those without a disability.

As with the general population, longer life expectancy among people with learning disabilities leads to an increase in the number living with dementia. People with learning disabilities also face an increased risk of developing dementia with increasing age compared to the general population, particularly those with Down syndrome. Alzheimer’s dementia is the most common type among people with learning disabilities.

Unit 5. Physical health and psychological well-being

Psychosocial problems may contribute to loss of skills in a person with dementia but can also be the cause of skills decline, rather than an organic dementia. These include:

- **mental health problems:** the most common differential diagnosis for dementia is depressive illness but other conditions, such as the exacerbation of an existing psychotic disorder, can also “mimic” the presentation of dementia
- **life events:** people with learning disabilities in middle age can face life events such as the loss of a parent or long-term carer, moving away from home or loss of day activities that may lead to a regressive state in some individuals with apparent loss of skills
- **abuse:** current or recent physical, emotional or sexual abuse in people with learning disabilities may result in loss of skills and regression and the development or exacerbation of behaviour problems that might superficially mimic dementia
- **impact of poor environment:** an unsuitable environment associated with lack of stimulation, isolation and lack of opportunities for positive interaction can lead to loss of skills.

Stress can be a significant issue for the family and paid carers of people with learning disabilities who develop dementia. The age profile of parents of children with disabilities tends to be higher, so parents may be elderly when a diagnosis is made and care needs become greater. The Caregiver Activity Survey–Intellectual Disability [CAS–ID] [McCarron et al, 2002] provides a measure of carer burden.



Further reading

- McCarron, M., Gill, M., Lawlor, B. & Beagly, C. [2002]. A pilot study of the reliability and validity of the Caregiver Activity Survey–Intellectual Disability [CAS–ID]. *Journal of Intellectual Disability Research*, 46, 605–612.

Sharing a diagnosis with client and carers

Sharing a diagnosis of dementia can be difficult. Steps should be taken to share information with the person with learning disabilities at all stages. Carers will also need support with end-of-life issues at a later stage of a progressive dementia. Input from a speech and language therapist can often be helpful to ensure that the client understands the information provided as much as possible. The focus should be on surviving skills, rather than losses, and opportunities for stress-free and failure-free activities.



Further reading

These resources may be helpful when sharing a diagnosis:

- Dodd, K., Turk, V. & Christmas, M. [2005]. *The Journey of Life, About My Friend and About Dementia*. Birmingham: BILD.
- Buijssen, H. [2005]. *The Simplicity of Dementia: a guide for family and carers*. London: Jessica Kingsley Publishers.
- Buckman, R. [1992]. *Breaking Bad News: a guide for health care professionals*. Baltimore: Johns Hopkins University Press.

Unit 5. Physical health and psychological well-being

Further reading (continued)

- Dementia Pack from Down's Syndrome Scotland:
→ www.dsscotland.org.uk
- Keep Talking about Dementia, available at:
→ <http://lx.iriss.org.uk/sites/default/files/resources/Keep%20Talking%20About%20Dementia.pdf>
- Alzheimer Scotland - Action on Dementia:
→ <http://www.alzscot.org>

Helping carers to understand Alzheimer's dementia

One approach to understanding Alzheimer's dementia and its psychological consequences was put forward by Buijssen (2005). He proposed two laws of dementia.

The law of disturbed encoding

The person is no longer able to transfer information successfully from his or her short-term memory and “store” it in the long-term memory. This means that he or she is unlikely to remember things that have just happened. The main consequence of disturbed encoding is that the person is unable to form any new memories for experiences or things they are told, resulting in him or her:

- being disorientated in an unfamiliar environment
- being disorientated in time
- asking the same questions repeatedly

- quickly losing track of conversations
- being less able to learn anything new
- easily losing things
- being unable to recall people recently met.

The law of roll-back memory

Long-term memory contains all the memories acquired, starting with the most recent and working back toward childhood. When dementia develops, the person will be less able to form new memories. Deterioration of memory will begin with the most recent memories and will progress until only memories of early childhood remain. Memory can therefore be considered to be “rolling back”, leaving the person with:

- loss of daily skills, such as using kitchen appliances
- memory loss for events, beginning with the most recent
- decreased social skills and increased inappropriate behaviour
- decreased vocabulary and ability to find words
- disorientation towards people, such as being unable to recognise family and relatives
- “flashbacks” and “seeing” people from their past
- deteriorating self-care skills
- changes in personality
- a belief that he or she is younger and that time has actually “rolled

Unit 5. Physical health and psychological well-being

back”.

Alzheimer’s dementia is a progressive and, at present, terminal illness. As it progresses, it becomes harder for others to ascertain the wishes of the person affected. Preparing the client and family or carers for the end of life is



Learning activity 5.3

Case study: Christina

The psychologist has now met with Christina and her staff a few times, but aspects of her behaviour and feelings that can’t easily be explained by emotional or psychological factors remain. He has suggested a baseline assessment of Christina’s cognitive functioning, to be repeated in six months, to see if dementia may be present. Staff are also beginning to suspect that there is something other than anxiety going on for Christina and, in discussion with her sister, agree that the baseline assessment should go ahead.

The psychologist calls Christina’s sister, who confides that she has been concerned about something like this happening to her or one of her sisters as her dad had started showing signs of dementia in his late 60s, just before he died.

After completing the initial assessment and with the help of some staff observational information, it is agreed that Christina has possible dementia in the early-to-mid stages. The psychiatrist prescribes a cognitive enhancer.

Christina’s behaviour does not improve greatly, but neither does it deteriorate significantly. Staff, however, are quite frustrated at the

changes in her needs and the different demands now placed on them. They are also upset at the thought that some of the things they do with Christina will have to stop or change as her needs progress.

Think about the above case study.

- **What could help staff support Christina through the difficulties they are all experiencing?**
- **What aspects of psychological care do you think could help Christina and her staff?**

therefore of particular importance.

Genetic syndromes

A number of genetic syndromes are associated with learning disabilities. Some are inherited from previous generations, leading to distress for parents or even grandparents if they are aware that they are “carriers” of the condition. Parents may question whether they are “to blame” to some extent for their child’s condition.

Down syndrome

The most common psychological difficulties encountered by people with Down syndrome are depression and anxiety, just as for the population in general, but difficulties such as repetitive and obsessive-compulsive behaviours are relatively more common among people with Down syndrome. The psychological consequences of Alzheimer’s dementia [the risk of

Unit 5. Physical health and psychological well-being

which increases substantially with Down syndrome] can exacerbate many psychological difficulties.

In common with people without learning disabilities, it is sometimes the case that changes in psychological well-being only become apparent when there is an additional stressor, such as death of a close family member or change in residential circumstances or daytime activity. When considering the potential reasons for any deterioration in a person with Down syndrome's psychological well-being, it is important to consider the possibility of the onset of a dementia and the role this may play in their presentation. Care should be



Further reading

- Hollins, S. & Curran, J. [1995]. *Feeling Blue*. London: Gaskell.
- Holland, A., Payne, A. & Vickery, A. [1998]. *Exploring Your Emotions*. Kidderminster: British Institute of Learning Disabilities.
- **Emily's story: the perspective of a person with Down's syndrome:**
→ <http://www.nhs.uk/Video/Pages/downsyndrom.aspx>
- **Victoria's story: the perspective of a parent**
→ http://www.nhs.uk/Video/Pages/cs_downsyndrom.aspx.

taken to avoid diagnostic overshadowing by ensuring that not all changes are **assumed** to be due to a single cause, such as Alzheimer's dementia.

Prader-Willi Syndrome

Prader-Willi syndrome is a genetic disorder characterized by (usually mild) learning disabilities and some physical and psychological features, which include almond-shaped eyes and smaller-than-usual hands and feet.

The most significant physical and psychosocial impact is related to food. A lack of feeling "satiated" after eating can, if left unchecked, lead to the person consuming three times as many calories as an average individual. The metabolism of a person with Prader-Willi syndrome is also slower, meaning he or she needs less calories to maintain weight.

Research has shown that individuals with Prader-Willi syndrome can be dissatisfied with their body but may find it extremely difficult to lose weight. This can lead to feelings of anxiety, anger and low self-esteem.



Further information

- **Can't Stop Eating: a documentary on Prader-Willi syndrome**
→ http://www.youtube.com/watch?v=Bjdg_Xi1uU0

Unit 5. Physical health and psychological well-being

Section 3.

Palliative care



Learning outcomes

By completing this section, you will:

- discuss end-of-life issues a person may face and how a learning disability might influence these
- discuss how choice in end-of-life care might be promoted
- discuss how people with learning disabilities might be prepared for death, and the psychological consequences
- discuss the psychological effects of death on a person's family and his or her paid carers.

In addition to these difficulties, problems with mental well-being and behaviour can also be common. It is suggested that there is some form of genetic basis to these behaviours.



Further information

- To view a film specific to people with learning disabilities on the Dying Matters website, access:
→ <http://dyingmatters.org/page/people-learning-disabilities>

End-of-life issues for people with learning disabilities

All people with learning disabilities will come to a dying stage of their lives, yet care professionals may be uncertain about how to talk to (and support) people at such sensitive times.

Promoting choice in end-of-life care

People with learning disabilities have more in common with the rest of the population than they have differences. If the differences (the learning disability, for instance) become the focus of care, barriers to accessing effective end-of-life care will be erected.

Communication is key to effective end-of-life care and support. The ACRCH model – ask, clarify, repeat, check and help – provides a checklist for carers:

- **ask:** find out what the person already knows – always use the person's name, use straightforward questions to find out information and ask what the person wants to know
- **clarify and repeat:** be prepared to go over information time and time

Unit 5. Physical health and psychological well-being

again in different ways (using books, photographs etc.) and simplify if necessary, listening carefully to the person and being guided by what he or she wants and needs

- **check** the level of understanding: explore how much the person knows about the illness and what it means to him or her, returning to previous stages if necessary and always being guided by the person



Learning activity 5.4a

Case study: Christina

Staff managed to support Christina through some very difficult times. They used the advice given to develop memory aids and put together life-story information, particularly more recent information to help new carers and Christina's sister.

Christina's dementia has progressed to the stage where it has become almost impossible to support her at home. It is no longer safe to leave her alone without night-time support. The local authority has agreed to put in temporary night cover until a new package of care has been agreed. A case conference is to be held to discuss future care.

Either by yourself, or with your mentor, consider the information above and answer the following questions.

- **Who should be invited to the case conference?**
- **Try to put together the agenda you think the group should discuss.**

- **What do you think people need to know/take into consideration when trying to agree an appropriate care package for Christina?**
- **What do you think is the most appropriate model of care for Christina now?**
- **How would you involve Christina in the process?**
- **How would you offer information to Christina on decisions made?**

- **help** the person to express feelings: encourage expression of feelings, listen carefully and focus on future support options and choices.

Time must be taken to discuss with the individual personal priorities for end-of-life care and treatment: various tools can be used for this following adaptation to meet the person's communication needs.

Preparing people with learning disabilities for death

There is evidence to show that people with learning disability who have been given opportunities to discuss their end-of-life care in a meaningful way have less likelihood of receiving unwanted medical interventions and reduced levels of depression. Their relatives and carers also deal much better with

Unit 5. Physical health and psychological well-being



Learning activity 5.4b

Case study: Christina

After much discussion, it was agreed that Christina's care needs would be best met in a residential care home specialising in dementia. It was also agreed that she would get some "social hours" from the carers who had been supporting her at home. Most had worked with Christina for more than three years and wanted to maintain contact, whether they were working with her or not.

Christina developed pneumonia just after New Year. She was very poorly and had to be moved to hospital. After two weeks, the doctors told her sister and carers that she was unlikely to survive for much longer and they would be starting her on an end-of-life plan. A number of decisions would have to be made, including whether to resuscitate Christina if necessary. The doctors asked what Christina's sister wanted them to tell her, but she wasn't sure. She'd never discussed issues of death with Christina but knew some of the carers had, so she decided to speak to them about this.

- How might the carers help Christina and her sister with these difficult issues?
- Should people be telling Christina what is happening? Do you think she would understand? What do you think is the best way of trying to help Christina understand what is happening to her?

- How could people try to make sure the things Christina wants to happen are done?
- Recall what the carers did in the past to help Christina deal with the death of Margaret, her carer. How could this help Christina's sister and them to deal with Christina's impending death?

Look at this and other examples of person-centred end-of-life care plans.

- http://www.pcpld.org/beta/wp-content/uploads/when_i_die_2_0.pdf
- Either by yourself, or with your mentor, write down some of the emotions someone with a learning disability may go through when preparing such a plan.
- How could you support such a person through the process?

Unit 5. Physical health and psychological well-being



Further reading

- You can access the “We’re Living Well but Dying Matters” webpage at:
→ <http://dyingmatters.org/page/were-living-well-dying-matters>

the bereavement process. Ensuring a holistic approach is central to all care planning, so family and friends should be involved wherever possible.

You’ve completed the resource...

We hope you’ve found this resource helpful in extending or consolidating your knowledge about psychological issues for people with learning disabilities. Most of the topics covered are relevant for anyone whether they have a learning disability or not, but some issues, such as stigma, are particularly pertinent for people with learning disabilities.

We hope the resource has helped you think about your own practice, perhaps increasing your awareness that you are using psychological knowledge already! Some topics, such as psychological therapies, may incline you to pursue further learning or training.

Please remember that some parts of the resource can be used to support the learning of other people, such as students or support staff. You might want to consider with your mentor how you could facilitate this.

We would also like to re-emphasise the fact that most people with learning disabilities do not develop psychological difficulties, even when life

Alternative Formats

This resource may be made available, in full or summary form, in alternative formats and community languages. Please contact us on **0131 656 3200** or email altformats@nes.scot.nhs.uk to discuss how we can best meet your requirements.



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