

MEETING THE CHALLENGE, MAKING A DIFFERENCE



Working effectively to support
people with personality disorder
in the community.

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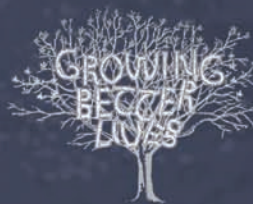
We are grateful to all those service users whose quotes have been included, and the experts by training and by experience who provided useful comments.


With thanks also to the authors of 'Working with personality disordered offenders in the community' (2011, *Department of Health and Ministry of Justice*), from which we have drawn ideas and some sections of text.

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Foreword

The last ten years have seen major changes in the way health and social care services work with people with the complex psycho-social difficulties known as personality disorder. Great strides have been made in developing new treatment interventions to support people in leading more fulfilling lives

At the same time, the government has provided additional funding for specialist and innovative services and the publication of guidance documents about workforce development and commissioning of services for people with personality disorder.

In 2003 the Department of Health published *No Longer a Diagnosis of Exclusion*, a guidance document which highlighted the failure of mainstream mental health services to identify and provide appropriate treatment for those with personality disorder or other complex psycho-social disorders. A programme to develop 11 community personality disorder services was established in 2005 with the aim of testing new service models and evaluating their effectiveness. The majority of these pilot services have since transferred into mainstream local provision and have led to steady growth in personality disorder services across the UK.

Breaking the Cycle of Rejection: The Personality Disorder Capabilities Framework, published in 2004, launched a major education and training initiative to improve the awareness, capability and competence of workforces across health, social care and criminal justice. A partnership between the Institute for Mental

Health Nottingham, Emergence (formerly Borderline UK), the Tavistock and Portman NHS Trust and the Open University established the Knowledge and Understanding Framework (KUF) which now offers a comprehensive education and training programme for staff working with people with personality disorder.

These initiatives, supported by NICE Guidance on Borderline and Antisocial PD in 2009, have opened the door to service development and most importantly, workforce training initiatives to ensure that services can better provide for those with complex psychological difficulties.

Meeting the Challenge – making a difference serves as a companion guide to *Working with Personality Disordered Offenders*, published in 2011. This present Guide is intended for community practitioners, and aims to bring up-to-date thinking about personality disorder into the daily work of thousands of staff working across health and social care services. Their committed work deserves support.

Nick Benefield,
Programme Director, Department
of Health Personality Disorder
Programme, 2004-2014

Executive summary

It's not personality disorder unless someone's difficulties are persistent, pervasive and problematic. Personality difficulties affect the way an individual characteristically feels about themselves and others, and may be evident in recurring problems in their relationship with others.

Personality disorder may be apparent in the person's account of their problems, their history, difficulties in engaging with services, or the way in which staff or services characteristically respond to them.

While there are sometimes benefits to establishing a formal diagnosis, this can be stigmatising. For most workers in the field, it is more helpful to work with the service user to arrive at a formulation of their difficulties.

There is no single pathway to developing personality difficulties or disorders. Difficult experiences in childhood can combine with biological vulnerability and social disadvantage to create a life course that leads to personality disorder.

Even though personality difficulties may be longstanding, there is a great deal that can be done to help people.

A helpful stance towards someone with personality disorder is to be curious and compassionate, trying to understand what the person is experiencing, and what is affecting their present feelings and behaviour.

Symptoms such as self harm require workers to deal in an effective way with risk and injury, while also remaining concerned about what has led the person to harm themselves.

Service users with personality disorders who may have experienced neglect, rejection or maltreatment, both within their families growing up and later when they have sought help, may be wary of accessing help.

Becoming involved in services – planning, evaluation, and delivery – are all ways that service users can make a highly valuable contribution and may discover new skills and talents.

Engaging with a person with serious personality difficulties can impact on staff emotionally. Look after yourself. Seek psychologically informed supervision and support, take time out to reflect, be realistic about change, and celebrate real progress.

"A lot of people see you
as untreatable."

You're not seen as a human
being but as a diagnosis.
Everything you do
is seen in that light."



PERSONALITY
DISORDER

Introduction

All frontline workers will encounter people who might be seen to have a personality disorder. Someone's personality is their characteristic patterns of thinking, feeling and behaving that remain fairly consistent across situations and over time. 'Personality disorder' is the term used within mental health services to describe longstanding difficulties in how an individual thinks and feels about themselves and others, and consequently how they behave in relation to other people.

THE PURPOSE OF THIS GUIDE IS:

- To help people to **know more and to understand more** about personality disorder, and how this impacts on individuals who may attract this diagnosis, and the staff, teams and organisations that work with them.
- To invite people to **think about their own attitudes** to working with people with personality disorder.
- To provide some **information about services** that might be available, how to access help for people with personality disorders, and what can be expected from services.
- To offer **guidance on helpful and unhelpful ways of responding** to people with personality disorders.

Sometimes it is our own reaction to a service user¹ that alerts us to the fact that this person struggles with relationships. We may find ourselves feeling uncharacteristically frustrated with someone, or eager to help and ‘rescue’ them from their difficulties, or feeling we have to tip toe around them for fear of provoking them. Sometimes these reactions are to do with our own issues, but sometimes it signals that this service user has personality difficulties and will need the worker to be particularly careful and thoughtful in their approach.

There are many different ways in which someone can have personality difficulties, or a personality disorder. These are three examples of people who have personality difficulties which interfere with their everyday life:²

Jack often reads hidden meanings into harmless remarks and is quick to feel injured or slighted and then reacts in an angry way. His family feel they have to tread carefully around him. His partner experiences him as suspicious and inclined to be jealous; he has accused her of having affairs. If he feels he has been got at or betrayed by friends he harbours grudges

and will not forgive and forget, so over the years he has lost friends and become increasingly isolated.

Kelly manages to hold down a job as a nursery nurse, but she struggles with mood swings, sometimes feeling OK, but often overwhelmed by anger or feeling depressed and worthless. Her relationships with partners start well but seem to ‘crash’ within a few weeks; she is very sensitive to feeling rejected or abandoned and partners can experience her as too demanding. When she feels hurt or rejected she can get in a rage and she sometimes lashes out at others, but she is more likely

¹ Throughout this guide the term ‘service user’ will be used to refer to people who might be given this diagnosis and who have accessed help from services. We have chosen to use this in preference to other terms in use to denote people in receipt of services, such as ‘patient’, ‘client’ or ‘customer’. We recognise that the term ‘service user’ is not ideal as some people feel it devalues the many aspects of individuals’ lives beyond their engagement with services. We use it here for ease of understanding but hold in mind these reservations.

² When examples are given, these are not real people, but are fictitious examples based on people we have known.

THE TERM 'PERSONALITY DISORDER' HAS BEEN CRITICISED FOR THE FOLLOWING:

- There is no clear cut-off between someone who has an unusual or troublesome personality, and someone with a 'disorder'.
- Individuals labelled as having a 'personality disorder' might feel that this marks them out in a way that is stigmatising or unhelpful.

to harm herself. Kelly finds it very difficult to be alone; when alone she feels empty and frighteningly unsure of who she is. When feeling desperate she sometimes cuts herself, and she took two overdoses in the last 2 years.

Susan has been suffering from anxiety and panic for over 20 years. She relies heavily on her teenage children, expecting them to accompany her whenever she leaves the house, and calling them on their mobile phones if she panics when alone. She also often calls the emergency services, imagining that she is having a heart attack when she has anxiety symptoms.

She has been repeatedly referred to mental health, IAPT and psychology services for treatment of her anxiety and agoraphobia, but has difficulty getting to appointments and has never stuck with any treatment programme. Her older daughter has recently been missing a lot of school

because she has been staying at home to care for her mother.

Do you recognize anyone with similar, longstanding difficulties amongst the people that you work with? If so, reading this guide may help you in your work.

When working with people who have personality problems, we do not want them to feel labelled, put down, or squeezed into diagnostic boxes. They are fellow human beings, many of whom have suffered greatly as they were growing up, and now struggle in adult life.

We want to help people on the road to recovery by working alongside them in a respectful way, working together, helping to build their sense of trust and confidence. The language that we use is therefore very important. Service users sometimes say that they do not like the abbreviation 'PD', or to be seen as nothing but a disorder.

A number of different phrases have been used to describe these

difficulties or people with these kinds of difficulties, including:

- 'Complex and severe psychological difficulties'.
- 'Complex needs' (this is sometimes also used to refer to people with severe mental illness).
- 'People diagnosable with personality disorder'.
- 'People who identify with the problems associated with the diagnosis of personality disorder'.

In this guide we are going to stick to using the phrases 'personality disorder' or 'personality difficulties' though we will describe some of the problems with these terms.

We all have personalities, and we all have aspects of our personalities that are troublesome at times. People with personality disorder are not fundamentally different from anyone else, but might, at times, need extra help.

WORKING TOGETHER

Professionals have come to recognise that working alongside service users with diagnosable personality disorder to plan, design and deliver services has led to better services and a better experience for everyone.

Service users' views are taken seriously, service users have the opportunity to hold valued roles and influence, and professionals get a much better idea of what is really needed and what really helps. This guide has been produced through service users ('experts by experience') working with professionals ('experts by training') in a collaborative and equal way.

"When I found out about
personality disorder
I knew I was not
The only one



who had
wacky moods w
and weird things
going on in my head."

1 What do we mean when we talk about 'personality disorder'?

We all have personalities – the collection of qualities and personal characteristics that make us distinctive as people. We all also make assessments of other people's personalities: we might describe one person as an extrovert, or another as shy.

Each person's personality has a number of different qualities or 'traits'; these may sometimes seem contrasting or contradictory: a person can be cautious with respect to money, but impulsive when it comes to making relationships; they might be very serious and dutiful at work, but humorous and warm with friends.

We all have parts of our personalities that cause us problems in some situations. For example, someone who generally copes well in life might be inclined to be irritable and suspicious when they meet someone new, or feel anxious when alone.

What is the difference between having aspects of your personality which can sometimes cause problems, and having a personality disorder?

The three 'P's'

For someone's personality difficulties to be considered a 'disorder', those difficulties must be Problematic, Persistent and Pervasive. Think about **'the three Ps'**:

- For someone to be given a diagnosis of personality disorder, the individual's personality characteristics need to be outside the norm for the society in which they live, to be a source of unhappiness to that person and/or to others, and/or to severely limit them in their lives. Those characteristics are **problematic**.
- Personality disorders are chronic conditions, meaning that the problematic characteristics continue over a long period of time, they usually emerge in adolescence or early adulthood, they are relatively stable and can continue into later life. The characteristics are **persistent**.
- These problematic characteristics result in distress or difficulties in a number of different aspects of someone's life, such as intimate, family and social relationships, how someone experiences the world around them, their relationship to themselves (that is, their inner world), and in any employment or occupation that the person takes part in. They can also affect the way in which the individual relates to

potential sources of help. They are present in most if not all aspects of the person's life. In other words, they are **pervasive**.

Diagnosing 'personality disorder' is a task for a skilled and trained professional. Labelling someone as having a personality disorder may have serious implications for them, and some people may be very upset by or disagree with the diagnosis. If someone is formally diagnosed as having a personality disorder, this diagnosis should be discussed with them in a careful and sensitive way. (For helpful tips see **Chapter 2**, Why is the diagnosis so controversial?).

Because of the dangers of casual or careless labelling, we would discourage you from labelling your clients as having a personality disorder unless you are professionally trained to do so. It is much more useful to think about them as having complex needs, or personality difficulties, and to think about what those are, and how they affect the person.

How common is it?

'Complex needs' or 'complex emotional needs' are quite new terms, and we do not yet have any figures about the proportion of people in different contexts who have complex needs. At present, the statistics we have tell us how commonly people meet the criteria for personality disorder. Different research studies come up with different results, but in general in the UK between 5% and 12% of the population would meet the criteria for a diagnosis of personality disorder. This means that it is quite common. In comparison, only about 1% of people will have at least one episode of psychosis at some point in their lives; at any one time, about 2% of people suffer from major depression. Some of the people who would meet the criteria for personality disorder have relatively mild difficulties and may only need treatment at times of stress, but there are many people living with disabling problems which impact on their wellbeing, their relationships, and their everyday lives.

How do I recognise when someone has personality disorder?

Different types of information may alert you to the fact that someone has a personality disorder. You will never find that all of these factors are present in one person, and some of these factors may be associated with other types of difficulties such as long term illnesses, but if a number of the items listed are apparent you might start to think about whether the person has enduring personality difficulties or complex needs.

1) HOW THE PERSON PRESENTS AND DESCRIBES THEMSELVES TO YOU

The person may describe one or more of the following:

- A long-standing pattern of emotional or relationship difficulties, like always finding themselves being let down, abused or abandoned by others.
- Feeling caught up in a whirl-wind of rapidly changing feelings, often overwhelmed, or overwhelming others, in the intensity of what they are feeling.
- A history of turbulent or unstable relationships.
- Feeling wary or suspicious, reluctant to disclose information despite your intention to help them.
- Long-standing personality characteristics which have always been a problem, like "I've never had any friends", or "I've always been painfully shy", or "I've never been able to bear being on my own", or "I've always wanted everything to be 'just so'".
- A difficult relationship to 'self' such as difficulties with identity, self-esteem, feeling 'different' to others, or a sense that they are failing in the world.

2) THE PERSON'S HISTORY

- Does the person have recurring patterns of **impulsive or self-destructive behaviour**, like self-harm, drug misuse, repeatedly provoking fights, repeated criminal offences, or an eating disorder?
- Is there evidence of **patterns in relationships which keep repeating**, like repeatedly getting sacked from jobs, repeatedly getting involved with abusive partners, or seeming to be exceptionally dependent on friends, family and services?

- People with personality disorder commonly report having experienced a range of **traumatic or unhappy experiences in childhood** such as physical, sexual or emotional abuse, being bullied, or witnessing violence within the family. Experiencing a single traumatic event is not usually enough on its own to cause someone to have personality disorder in adulthood, but negative factors in childhood can add up to make the person's start in life very difficult.
- Have they had a **number of hospital admissions** for mental health problems, which do not appear to have resolved their problems? Or a history of seeking help from doctors for a range of physical symptoms which have been fully investigated but for which there seems to be no explanation?
- Are there **frequent emotional crises** perhaps evident in repeated trips to A&E, or GPs?
- Is there a history of previous **suicide attempts or self-harm**?

3) DIFFICULTIES IN ENGAGING WITH SERVICES

- Is there evidence of previous **difficulties in relation to accessing services**? They might have dropped out of treatment, not kept appointments, become aggressive and been excluded from services, or have a history of making complaints. This may have been a response to inadequacies in the service, or reflect the individual's difficulties with engagement.
- Have they had a number of previous **treatments for psychological problems which seem to have failed** or not worked?

4) SOMETHING UNUSUAL IN HOW YOU OR THE SERVICE RESPONDS TO THIS INDIVIDUAL

Sometimes it is our own reactions, or the response of our colleagues or our agency to an individual, which alert us to the fact that this individual brings out an unusual reaction in people. We find ourselves reacting to someone in a way which seems uncharacteristic or hard to explain.

Sometimes these reactions reflect our own shortcomings; with greater training or experience, or support from colleagues, we can overcome or manage such feelings. But sometimes it does seem as though these strong reactions are a response to the particular individual and how they see themselves and others.

QUICK QUESTIONS:

If you only have a few minutes, and want to assess whether someone might have a personality disorder, Paul Moran and his colleagues have developed 8 simple questions which you can ask (Moran et al 2003). If the person answers yes to several of these questions, and thinks that the description applies most of the time and in most situations, it may alert you to the possibility that they have personality difficulties and indicate the need for a fuller assessment.

- 1) In general, do you have difficulty making and keeping friends?
- 2) Would you normally describe yourself as a loner?
- 3) In general, do you trust other people?
- 4) Do you normally lose your temper easily?
- 5) Are you normally an impulsive sort of person?
- 6) Are you normally a worrier?
- 7) In general, do you depend on others a lot?
- 8) In general, are you a perfectionist?

What do you do if you identify that someone has personality difficulties?

If you recognise that someone has personality difficulties, think about:

- How **severe** are the person's personality problems and what level of help might they need? (see following).
- What is your **agency's role** and what is it appropriate for your agency to do? (In **Chapter 4** we look at what you might be able to do to make a difference, whatever your particular role).
- Are you **comfortable to work** with the person with your current level of training and support?
- Would you be able to work with the person yourself if you had some **extra support** (training, supervision, team support, peer support)? (In **Chapter 7** we explore what support staff need in order to do this kind of work).
- What **other resources** are available locally? (In **Chapter 5** we describe the range of resources that may be available within your local area).

DO YOU FIND YOURSELF RESPONDING TO THE PERSON IN A WAY THAT YOU FEEL IS UNUSUAL FOR YOU?:

- Forgetting about them or feeling reluctant to engage with them
 - Making an exception and offering them special treatment
 - Hotly disagreeing with colleagues about how the person should be treated
 - Feeling useless and as though you have nothing to offer
 - Feeling overwhelmed by the person's needs
 - Finding yourself responding less sympathetically than usual
- Are there **unaddressed risks**, and if so, what needs to happen to address these?
 - Is there a need for a **crisis plan**, and if so, can you or your agency offer this, or should another agency be involved?

Even if it is not your agency's role to provide psychological treatment or counselling, there may be a great deal that you can do to help the person.

When to worry

It is impossible to write an exhaustive list of situations that should ring alarm bells, but here are some examples:

- 1) Escalation in risk associated with episodes of self harm or challenging behaviour.

Sometimes this indicates that the person is trying to communicate their need for help with increasing desperation, but sometimes it signals that there has been a shift from the person self-harming to actively trying to take their own life. It may also be the case that the behaviour threatens their life, without them necessarily intending to commit suicide. For example, a person who overdoses on medication as a method of self-harm, may, over time, increase the amount they are taking to the point where it poses a risk to life even though their intention was to harm themselves rather than commit suicide.

- 2) Evidence that someone who has previously

taken overdoses is stockpiling tablets.

- 3) If the person is unable to control emotional and angry outbursts and is living with children or vulnerable adults.
- 4) If someone who struggles with relationships becomes very withdrawn, barely leaves the house or their computer, and is at risk of neglecting self-care and eating.
- 5) If personality difficulties are contributing to the breakdown of housing, employment and relationships and there is a risk of homelessness.
- 6) When someone with a history of violence to strangers starts to be violent to a partner.

Some of these situations may require other agencies to be involved, such as mental health services, the police or social services. In other situations, it may be enough to ask the person what help they need and to think with them about how they might get it. If you remain worried, seek advice from within your own organization, and think about whether the person needs a specialist assessment or input.

HOW SEVERE ARE THE PERSON’S PERSONALITY PROBLEMS?

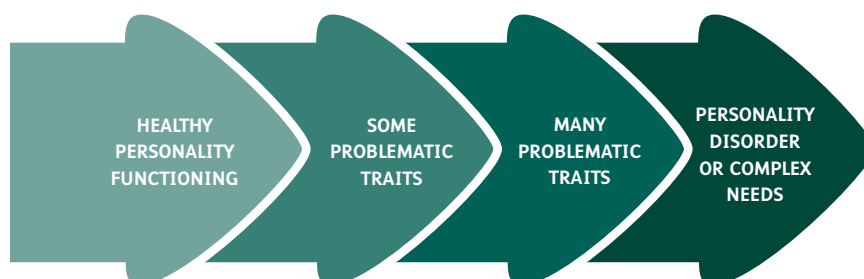
All of us have within our personalities areas where we function well, and areas where we function less well.

FUNCTIONING WELL	NOT FUNCTIONING WELL
Able to be flexible, to adapt to different situations, able to respond effectively most of the time.	Stuck in a particular way of viewing or relating to others, repeatedly feeling bad about how we are in social situations, responding to others in a way that is not helpful and often causes distress to them and/or ourselves.

It is important to be alert, not just to more ‘dramatic’ symptoms like self harm or aggressive outbursts, but also ‘quieter’ symptoms, like someone becoming very withdrawn, isolated, and starting to neglect themselves. In **Chapter 4** we think about what you can do to make a difference, and in **Chapter 5**, what other help might be available.

A CONTINUUM OF PERSONALITY FUNCTIONING

It is helpful to think of personality difficulties as existing along a continuum, with adaptive personality functioning at one end and personality disorder or complex needs at the other end, as illustrated below:



THE RANGE OF SEVERITY OF PERSONALITY PROBLEMS AND THE DIFFERENT INTERVENTIONS THAT MIGHT BE HELPFUL

<p>HEALTHY PERSONALITY FUNCTIONING</p>	<p>Anna is a teacher who regularly puts on school plays. She takes great pleasure in the children’s delight, and in the response of the audience. She enjoys the applause and the appreciation for her hard work, but is happy to step back and let the children be the stars of the show.</p> <ul style="list-style-type: none"> • Anna is unlikely to need or want help with this aspect of her life
<p>SOME PROBLEMATIC TRAITS</p>	<p>Angela is a music teacher at another school, where she has a reputation for organizing outstanding concerts. The quality of the children’s work is very high, but some parents feel that she drives the children too hard to excel, often losing her temper with them if she thinks they are not working hard enough. Her friends know that if she thinks the performance is less than perfect she will be miserable for days</p> <ul style="list-style-type: none"> • Angela might benefit from some short-term counselling or self-help information to help her see that her very high standards are problematic and can make her unhappy
<p>MANY PROBLEMATIC TRAITS</p>	<p>Annabel is a teacher at a third school. She is known for demanding very high standards from herself and everyone she comes into contact with, and for losing her temper very easily if she feels criticised or slighted in any way. Annabel works extremely long hours and sleeps very badly, feels very stressed and has repeatedly sought help from her GP. Her colleagues and acquaintances feel they have to tread very carefully around her so as not to spark off an outburst. Annabel feels anxious, unappreciated, and wonders why she does not have more friends.</p> <ul style="list-style-type: none"> • Annabel’s problems are pervasive and she might benefit from some psychological therapy to explore the range of situations that cause her difficulty
<p>POSSIBLE PERSONALITY DISORDER</p>	<p>Anne-Marie has not worked for several years. She started out as an art teacher but left teaching after a number of uncontrolled outbursts at work led to her being disciplined. She could not stand having to fit in with the strict timetable and demands of the job. She tries to paint, but swings between feeling that she is an exceptional artist and that people should recognise her talent, and feeling that her work is worthless rubbish. She has had a number of intimate relationships, but she is quick to feel that she is being let down or misunderstood, and relationships tend to deteriorate into jealous arguments and physical fights. She has always cut herself when very stressed, but recently this has been getting more frequent and more severe. Her life feels empty and depressing and she holds onto the thought that, if things got desperate, she could always kill herself.</p> <ul style="list-style-type: none"> • Anne-Marie’s difficulties are persistent, pervasive and problematic. She may need longer term or specialist help from a personality disorder service or team.

How do we describe and understand these problems?

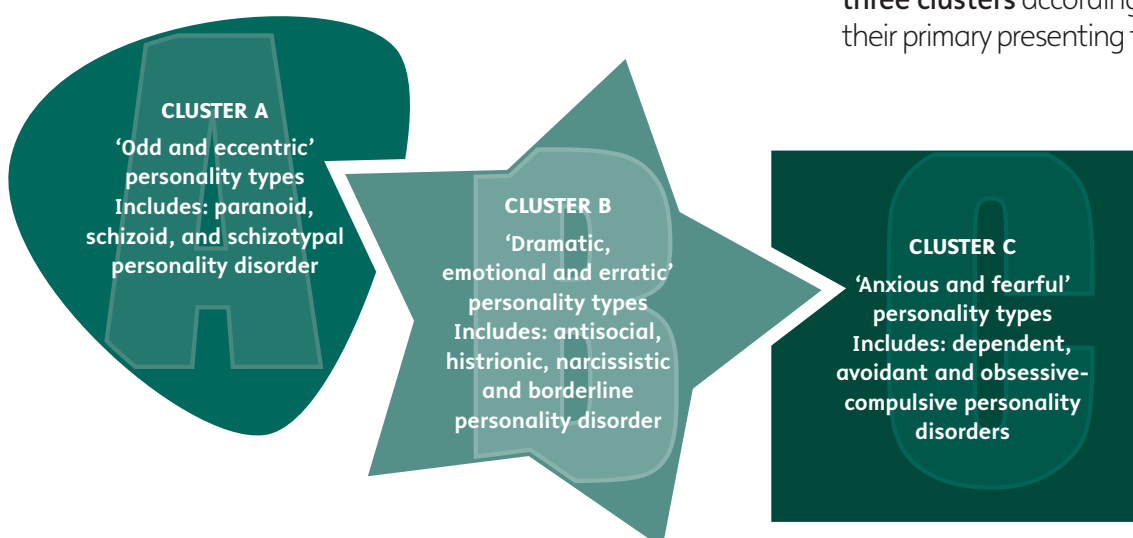
There are three main approaches to thinking about these kinds of problems:

- 1) Medical-type diagnosis, identifying whether people have problems that fit certain defined **diagnostic categories** of personality disorder.
- 2) Looking at how personality varies for each person along a continuum, sometimes known as the **'dimensional'** approach to personality.
- 3) A **formulation based approach** using psychological theory to help us to understand what anxieties or dilemmas lie beneath the surface behaviours, how these difficulties have developed, what maintains them and how are they triggered.

Each of these approaches has something valuable to contribute to building a full, clear and informative picture of someone's difficulties.

1) THE CATEGORICAL APPROACH TO DIAGNOSIS

In mental health as with physical health, diagnoses are made so that we can make a summary statement which should communicate to other people what problems an individual has, and which may provide some pointers about which treatments are likely to be helpful.



Different types of personality disorder:

Although the term 'personality disorder' is in everyday use, in practice there is much disagreement between people who work in and study this area of human life, about how to think about, describe, categorise and label difficulties of personality functioning.

Different classification systems are used for diagnosis. The American Psychiatric Association has a system known as DSM (Diagnostic and Statistical Manual) which has been revised a number of times. The fifth revision (DSM 5) was published in 2013. Both DSM 5 and DSM IV which preceded it, define **10 personality disorders** in terms of the traits, attitudes or behaviours which are characteristic of each. The disorders are also grouped into **three clusters** according to their primary presenting features.

To meet the threshold for being diagnosed with a personality disorder, DSM specifies that a person must have a certain number of the possible characteristics for that disorder (often 4 or 5 out of 8 or 9 possible characteristics). A diagnosis of personality disorder cannot be made on the basis of just one or two features.

Many people equate personality disorder with borderline personality disorder, which is characterized by someone having unstable relationships, self image and emotions, as well as impulsivity. Within the Criminal Justice field, people often equate personality disorder with antisocial disorder, which is often (but not always) associated with an offending history. It is important, when we talk about 'personality disorder', to be aware of the range and variety of personality difficulties that can cause severe problems for people.

However, there are many problems with this 'categorical' system of diagnosis:

- Many people have more than one diagnosis of personality disorder.
- People given the same diagnosis may have markedly different problems.
- Clinicians often disagree about which type of personality disorder an individual has.
- With many illnesses there is a clear distinction between a person with the illness, and someone who does not have the illness, but there is no hard and fast cut-off between a normal personality, and one that is considered 'pathological'.

As a sign of how confusing this area is, clinicians and researchers tried to propose major changes in how personality disorder was diagnosed for DSM 5, but could not agree how this should be done, and so ended up sticking with the existing system.

DSM is developed in the USA. An alternative model, widely used in the UK, is the International Classification of Diseases (ICD) developed by the World Health Organisation. The system in current use, ICD 10, describes 9 types of personality disorder,

The advantages and disadvantages of being diagnosed with a personality disorder will be discussed further in **Chapter 2, 'Why is the diagnosis so controversial'**.

2) THE 'TRAIT' APPROACH OR DIMENSIONAL APPROACH TO PERSONALITY

Most people working in this field now accept that personality does not fit neatly into categories or 'disease entities'. Instead, it is now recognised that personality traits and difficulties vary in how much they impact on someone's life (severity) and in the specific aspects of their personality that are affected (different dimensions). In recognition of this, proposals for ICD 11 include reference to the severity of impairment in personality functioning, and the nature of problematic personality traits.

Psychologists have attempted to identify the key dimensions that make up 'personality'. Although not everyone agrees about the structure of personality, most modern theories of personality suggest that it consists of a number of broad qualities or 'domains' with each of these domains having a number of component aspects, or 'traits'. One of the most widely accepted models is the 'Five Factor Model' of personality.

The **Five Factor Model** suggests that personality can be summed up by thinking where someone falls along the following five dimensions:

- 1) **Openness** (seeking out new experience , being curious, versus being more consistent and cautious)
- 2) **Conscientiousness** (the extent to which someone shows self-discipline and is dutiful, organized and plans in advance, versus someone being more carefree or careless)
- 3) **Extraversion** (whether someone is outgoing and sociable and seeks stimulation in the company of others, or whether they are more solitary and reserved)
- 4) **Agreeableness** (whether someone is friendly and shows concern for others, or whether they are more suspicious or antagonistic to others)
- 5) **Neuroticism** (whether someone tends to experience a range of unpleasant emotions easily, such as anger, anxiety and depression, or whether they are secure and confident).

An international group of experts have been working on a revision of ICD10 that will lead to an up-dated system, ICD 11. They question the usefulness and validity of ‘categories’ of personality disorder, and propose a more dimensional model. In ICD11, personality disorder is likely to be diagnosed by the severity of ‘personality problems, rather than whether they match a defined ‘category’ such as borderline or avoidant personality disorder. Apart from normal personality, there are likely to be four graded levels, ‘personality difficulty’ which will not be coded as a mental health disorder, ‘mild personality disorder’, ‘moderate personality disorder’, and ‘severe personality disorder’.³ In addition to establishing degrees of severity, personality will be assessed in four domains:

Internalising/ emotional/neurotic	Anxious, poor self-esteem, shyness, dependence on others
Externalising/ antagonistic/ sociopathic	Irresponsible, lack of regard for the needs of others, aggressive, deceitful
Detached/schizoid	Aloof, indifferent, reduced expression of emotion, suspicious
Anankastic	Over-conscientious, excessive orderliness, perfectionism, inflexibility, cautiousness

This dimensional model fits with the idea that we all have personalities that vary on roughly similar dimensions.

3) PSYCHOLOGICAL FORMULATION BASED APPROACH

Clinicians who provide therapy to people with personality difficulties and disorders (this includes psychiatrists, psychologists, psychotherapists and counsellors) may use diagnosis as a starting point, but usually they also attempt to develop a **psychological formulation** that will guide the psychological treatment.

A psychological formulation is an attempt to describe and explain a person’s problems in terms of the range of factors which contribute to the development and maintenance of the problems. Its purpose is to guide interventions and risk management strategies. Unlike psychiatric diagnosis, it aims to capture what is **individual and unique** about the person.

There are a range of psychological theories that can be used to structure a formulation, including learning theory, information processing theory, psychoanalytic theory and attachment theory. Each of these theories provides a framework for organizing and linking the information that we have collected about a person during the assessment process.

³ The exact names of these degrees of severity and domains may differ in the final document.

The aim is to **identify patterns which connect childhood development and adult personality**, so that we have an understanding of the person's history, and how they come to have these problems. We can then design an intervention to help them to overcome their difficulties.

Thinking about the individual, and arriving at a 'formulation' of their difficulties

A **formulation** is like a thumbnail sketch of a person, our best understanding at that point in time of how the person developed these problems, how they affect them now, what triggers them and what implications this has for how we should treat them. It's very helpful to write it down but always with a willingness to modify it as new information becomes available or on the basis of the service user's response to our intervention.

A useful model of formulation is called the '**Five P**' model:

PROBLEMS	It is always important to work to develop a shared view with the service user of what the problems are that they need help with. Their experience of their difficulties won't always tally with yours. You might think that they need to stop using drugs and alcohol but they may feel they need help with their relationships first of all. In order to engage them effectively it is necessary to take seriously their point of view. For example, their alcohol and drug use may be a way of coping with relationship difficulties, so working with them on the relationship issues may open the door to addressing their drug and alcohol use.
PREDISPOSING FACTORS	These are early childhood experiences, such as trauma, neglect and deprivation that increase vulnerability in adult life. An understanding of how these affect the person's adult personality will inform you of how they are likely to respond to your efforts to help them. This hopefully will help you to be prepared for the kind of difficulties in the relationship that may arise.
PRECIPITATING FACTORS	These are factors currently present in the person's life that trigger the problems. These can be triggers in the mind or in the external environment, such as recent loss of a relationship, or substance misuse. Identifying these triggers, in partnership with service users, can be of great practical help as it is something concrete that you might be able to help the person to change or reduce.
PERPETUATING FACTORS	These are factors which maintain the problem, that is, make it more likely that the problem will continue to recur, for example lack of support, or only being cared for when you are in crisis. Again, it is important to do this in collaboration with the person experiencing the problems as different people experience the same circumstances in different ways
PROTECTIVE FACTORS	These are factors which contribute to the person's resilience and capacity to cope with adversity. Relationships, employment, housing, and a support network can sometimes increase stress, but very often they work to promote resilience. If you can harness them in your work to overcome problems you are more likely to be successful. Again, it is important to identify these collaboratively with the individual, as they may well draw on resources which are not obvious to others.

“Music has got me through some of the most difficult times of my life, I don’t have any family and find friendships complicated, but sometimes when I have hit a crisis, I find solace and understanding in music. This ‘connection’ that I find in music has been ‘there’ for me in a way no actual person has.”

These five P’s are different from the three P’s described earlier, for identifying personality problems (persistent, pervasive and problematic). If you can work with the individual in your service to identify these ‘five P’s’, it will provide a sound initial framework for thinking about the person, what might be affecting them, and where there might be scope to help them to make changes. It is usually **difficult to change the predisposing factors** because these are part of someone’s history, but you may be able to help the person to **avoid or challenge the precipitating and perpetuating factors, or to strengthen the protective factors** in their lives.

Cultural differences and value judgments

The judgments we make about desirable and undesirable personality traits are sometimes very subjective, and reflect our own cultural context. In one culture, young people breaking away from their families and showing independence may be seen as mature and impressive; in another culture, continuing dependence on and close involvement with the family may be praised and seen as a mark of health. This is one reason why staff in mental health services and other agencies who work with people with personality disorder need to engage in ‘reflective practice’ with others. They need the opportunity to check out their judgments with a range of others to guard against the possibility of their own cultural attitudes negatively influencing their perceptions of service users.

“When I first saw a psychiatrist I was a young gay woman, embedded in gay culture – that was my ‘normal’ so when I saw in my notes that my short hair and boyish clothes were written about as a sign of something weird, I flipped out. The psychiatrist was an old, straight, white man – what the hell did he know of my culture? If he’d ever been to a gay club he would have known that I looked like most of the other women there. To his credit, once I calmed down and explained this, he did remove that section from my notes. But it made me wonder what other assumptions had been made about me...”

The definition of personality disorder given in DSM IV states that there must be an **“enduring pattern of inner experience and behavior that deviates markedly from the expectations of an individual’s given culture”**, but in today’s complex world we often engage with more than one culture.

Is the culture of a second generation immigrant that of the family he or she grew up in, or the culture of the wider community in which he or she went to school?

This is why the phrase in the DSM IV definition is very important: that the problematic pattern of behaviour 'leads to distress or impairment'. Sometimes being extreme or unusual within a particular culture is adaptive and functional: it enables people to challenge the status quo, and to achieve extreme or exceptional things like the early feminists or civil rights activists. When this is the case, if they do not harm others or feel distress themselves in the process, we may think of them as eccentric maybe, but 'high functioning' and not suffering from a mental disorder.

Distinguishing personality disorder and mental illness

Within a psychiatric framework for understanding mental health problems a clear distinction is made between personality difficulties and 'mental illness' such as severe depression, psychotic disorder and bipolar disorder. However, this distinction rarely reflects individual experience; it is common for people to have a range of difficulties, which this model would see as mental illness **and** personality problems; health professionals call this 'co-morbidity'. Some people are now questioning whether it is helpful to see someone as having **two** or more disorders, rather than viewing them as a person whose problems have different aspects. For example, many people with personality disorders use drugs and alcohol to help them manage their feelings. If they become dependent on substances some people would regard it as an additional disorder (a 'co-morbid' disorder) rather than part of the same underlying problem. Service users generally want to be treated as individuals, seeking supportive, empathic staff to help them navigate through the difficulties they experience in life, rather than being seen to have a number of disorders.


As discussed earlier, there is controversy about using a psychiatric approach to understanding emotional distress. However, it is widely used, and a distinction is often made between 'mental illness' and 'personality disorder' based on the following:

- Unlike personality disorders, mental illnesses are thought to have an identifiable onset, in which a period of 'illness' interferes with the individual's usual way of functioning. In contrast, personality disorder is more developmental, so there is no identifiable point in time when someone becomes unwell.
- Severe mental illnesses are traditionally treated with medication with the aim of returning someone to a state of wellness, although fluctuations can occur. In contrast, the difficulties associated with personality disorder form part of the personality system; medication may have a part to play but will not be the main component of the help required. People with personality disorder have long term problems, and do not have a healthy self to return to, but rather need to build one.
- Despite these distinctions, some people diagnosed with personality disorders also meet the criteria for 'mental illnesses' such as depression, psychotic disorder or bipolar disorder. It is also suggested that having a personality disorder may increase one's risk for developing mental illness.

LEARNING POINTS FROM CHAPTER 1

Personality difficulties or personality disorder mean that people have difficulties in lots of different areas of their life; you are likely to see this reflected in the range of problems that a person needs help with and in the ways that you and your organisation feel about and respond to them.

- We need people who are extreme and unusual as well as people who are more 'ordinary' to function well as a society. It is usually helpful to focus on personality characteristics that cause **problems**, rather than those we might consider **unusual**.
- For someone's personality difficulties to be considered a disorder, they must be **pervasive, persistent and problematic**.
- Criteria exist to determine whether someone has a personality disorder; unless you have been trained to make diagnoses, it is usually more helpful to arrive at a personalized **formulation** about how someone's problems seem to have come about, what triggers and perpetuates them, and also what might enable them to change.



*"After years of desperation,
of suicide attempts,
hospital admissions
and a body pumped full of medication,
they have given me this label
and walked away."*

2 Why is the diagnosis of personality disorder so controversial?

The term 'personality disorder' is a psychiatric one, drawing on a medical framework for understanding behaviour, emotions and psychological distress.

There is no underlying ‘disease’ in personality disorder. There are no biological markers or signs that someone has a personality disorder. The term is a form of shorthand to describe a range of psychological characteristics that give rise to patterns of emotion, behaviour, relationships and thinking. The label ‘personality disorder’ cannot be used as an explanation and it can only be judged by its usefulness.

Personality disorder is a familiar term to staff working in mental health services. Many other agencies also work with people who have problems associated with the diagnosis, such as social services, housing and voluntary organizations, and they may not use this term. They will recognize and encounter the difficulties experienced by their service users, but are likely to describe them in terms more relevant to the task of their agency. For example, housing support agencies may describe a service user as having difficulties maintaining a tenancy, rather than as having a personality disorder.

They may neither understand, nor feel they need to know, why the problem arises. One of the difficulties with the term ‘personality disorder’ is that it may give a mistaken impression that we now have an explanation for the person’s

problems – for example, the reason they struggle to maintain their tenancy is because they have a personality disorder. In fact, this explains very little because it tells us almost nothing about the nature of the person’s particular difficulties.

The diagnosis of personality disorder is controversial. This is because of the qualities often associated with such a diagnosis in many people’s minds, and because of mental health services’ history of marginalizing and excluding such people because they were not seen to have a treatable ‘illness’. We now know that personality disorder is treatable; the vast majority of people can benefit from the right support at the right time. However the idea that personality disorder is untreatable still lingers and has contributed to many service users not wanting to be associated with the diagnosis.

“A lot of people see you as untreatable. You’re not offered the help and support. You’re not seen as a human being but as a diagnosis. Everything you do is seen in that light.”

“With panic disorder and depression I received help. With personality disorder I was treated differently, I had no help.”

Stigma

Many service users, carers and mental health professionals strongly dislike the term ‘personality disorder’ because it is seen as invalidating to their whole identity and sense of self. It implies a criticism or judgment, rather than a description.

Personality disorder is also linked in the public mind with criminality and dangerousness; in fact, the majority of people with difficulties associated with personality disorder are not violent or criminal.

REFLECTING ON EXPERIENCES OF STIGMA AND DISCRIMINATION:

Many of us understand what it is like to be stigmatised from our own experience in society.

Are you...	<ul style="list-style-type: none">- Black or from a minority ethnic group?- Lesbian, gay or bisexual?- Transgendered?- Female?- Disabled?- Religious?- Ever been unemployed/needed benefits?
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It takes considerable emotional resilience to deal with people making judgements and assumptions about you.

For someone who already feels vulnerable and like an outsider who does not 'fit', as many people with personality disorder do, then it can be very difficult to face stigma.

"I became a 'services leper'. I was told by the psychiatrist I had been blacklisted. After the diagnosis was made I felt excluded. There was a general unwillingness to help and I was refused treatment."

"I was treated less sympathetically because of personality disorder. They believe it's not mental illness but something you've brought on yourself."

"I think the diagnosis is saying 'trouble maker'. You're ignored. People can be hostile. You're not taken seriously. People don't believe there's anything wrong with you if you've got personality disorder."

Personality disorder has been called 'a very sticky label'. When it comes to personality, people often assume that we cannot change, 'the leopard can't change its spots'. Actually, we know that people can change very considerably, sometimes through professional help, but also through forming helpful relationships, having good experiences, and through the passage of time. But, once someone has that label, it can be difficult to persuade others that they have changed.

The notion of treatability

For many years, people given the diagnosis of personality disorder were regarded as ‘untreatable’ and were either excluded from services or severely marginalized within them. On the edges of services, psychotherapists and psychologists had been providing treatment to people who had problems associated with the diagnosis for many years. By the 1990s, evidence was beginning to emerge from a number of research trials that some of these psychological treatments were effective. But generic mental health services continued to regard the problems associated with personality disorder as untreatable. This seems to be because the notion of treatability was largely defined medically within the 1983 Mental Health Act. It meant treatable by medication. No one thinks the psychological and emotional difficulties of personality disorder can be cured by medication (though some aspects, like symptoms of depression or anxiety, can be helped by medication). So people with personality disorder were dealt a double blow: they were stigmatized by a diagnosis that many experienced as attacking of personal identity, and without access to any form of help or treatment.

Over the last 10 years, this has changed to a degree. A combination of government policy and some investment in innovative specialist personality disorder services has increased the range of provision and gone some way towards improving accessibility (see **Appendix 2** for links to policy documents that were important in bringing about change, such as ‘Personality Disorder: No longer a diagnosis of exclusion’). However, provision and accessibility remain extremely patchy. Where a person lives still determines whether they can get treatment and support from statutory services.

Why give a diagnosis of personality disorder?

While many people believe the diagnosis is not useful or valid, others feel a sense of relief on receiving it. The label can be stigmatizing but the diagnosis also helps some people to make sense of their experience and enables them to put a name to things they grapple with but are difficult to explain. Being given a diagnosis also enables people to become more informed about different treatment options, what other people have found helpful and about the issues themselves. It can also help people feel less alone, and more part of a community of likeminded others. It enables people to seek out peer support and connect with others who have a shared experience, which can be extremely powerful. Where there is local specialist service provision, a diagnosis is also the key to unlocking this.

Specialist personality disorder treatment services almost always have entry criteria which include a formal diagnosis. For these reasons, the diagnosis can be helpful and useful for some people.

“I was pleased and relieved to have the diagnosis of PD. I had read about it and it was like I was reading about me. It always felt as if I had more than depression, and when I found out about PD I knew that I was not the only one who had these wacky moods and weird things going on in my head. I have joined a support group and know that I am not mad ‘cos there are others just like me and they are okay, so I might be as well.”

It matters how a diagnosis is given

Research carried out by Emergence in partnership with St. George’s University (Turner et al, 2011) shows that how individuals receive and understand their diagnosis has a direct bearing on their aspirations and expectations of recovery, often limiting their hopes.

Some of the quotations in this section were taken from two research studies interviewing service users carried out in North East Essex in 1999 and 2009. When asked how they discovered they had been given a diagnosis of personality disorder, many people had made this discovery indirectly from records, reports, or at social services meetings. Others appeared to have been told about the diagnosis after many years; yet others were told by professionals only after they asked.

Reactions to finding out about the diagnosis included anger, feeling insulted, feeling blamed, depressed, anxious, daft, abnormal, numb, bewildered, mystified, helpless, shocked and excluded.

“At the review nobody took time to explain the diagnosis to me and all the discussions took place about me, but not involving me. I remember feeling numb and bewildered, as if everyone knew except me. I felt as if there was little or no hope for me.”

“After I was discharged I opened a letter from my psychiatrist to the GP. It said it there. I was a bit stumped, shocked. I’d heard about people that had been diagnosed with personality disorder being the black sheep of the community. It made me feel I didn’t belong anywhere.”

For many years, because of the controversy about the diagnosis, some practitioners have chosen not to share the diagnosis with the service user. Although there are challenges to giving people this diagnosis, if someone has been formally diagnosed with personality disorder, we recommend sharing this information with the individual themselves. Many of the benefits of having a diagnosis are only available if it is shared with the service user, such as feeling less alone, being able to find out more about the difficulties and how others have survived similar experiences. One of the key elements of working effectively with people with these difficulties is an emphasis on the relationship between staff and service user. Service users cannot make informed choices or work in partnership with staff to develop support plans/formulations and so on, if their diagnosis is hidden from them.

It's not the label that matters but what happens afterwards.

“They have given me the label Borderline Personality Disorder. I don't seem to be getting a referral to any kind of service, or any help that I need. After years of desperation, of suicide attempts, hospital admissions and a body pumped full of medication they have given me this label and walked away.”

“My brother is now in his 50's and has suffered all his adult life with OCD and PD. Good PD services are not available in the area in which he lives so he has had to 'make do' with a weekly general mental health group which keeps him 'well enough to work' but does not address underlying issues. I am sure that, should good services have been available, he would now be living a much more worthwhile and fulfilled life, rather than just existing from day to day.”

There is now a view that if the label has some advantages, it can be tolerated, as long as the person is informed of the diagnosis in a way that feels supportive and informative. When giving the diagnosis or discussing it with a service user, it is helpful to refer to the controversy surrounding it, and the discomfort many people feel in using it. Explaining that it is actually shorthand for 'complex and long term emotional and psychological difficulties' and does not imply any judgment or blame, is likely to be reassuring, especially if accompanied by an offer of appropriate treatment and support.

“Being in a place where I thought my only option was death, I was so grateful when I was told (a) I possibly have Personality Disorder (PD) and (b) that Complex Needs exists and they could help me. I cannot stress enough that being told that gave me such hope.”

Supporting someone through the process of receiving the diagnosis

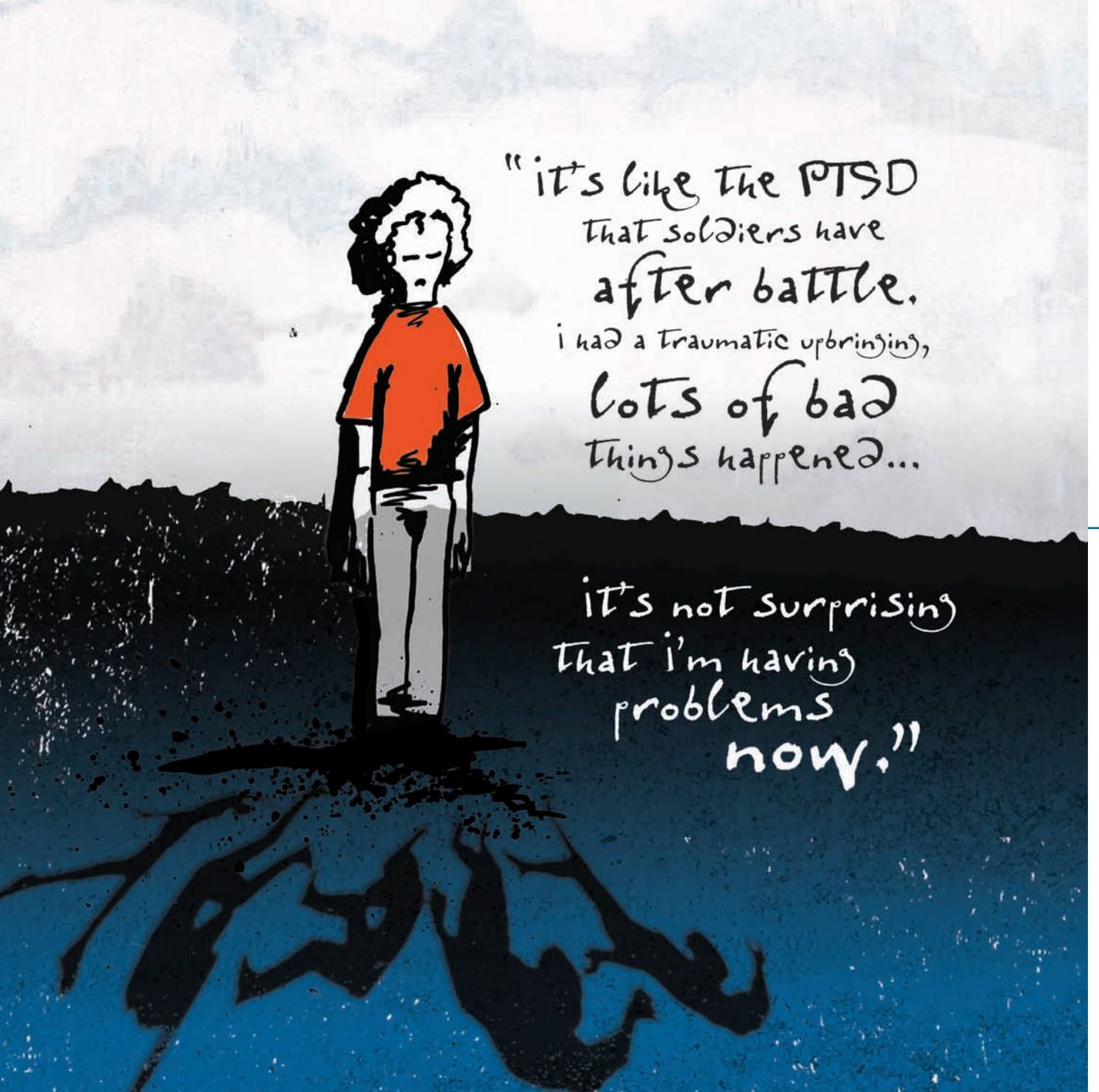
Whether or not the person understands the meaning of the diagnosis they have been given, they are probably aware of its stigmatising effect and will likely need support to process being given the diagnosis. Regardless of your role, individuals may well want to talk this through with you so here are some ideas to support the process:

- Give people time to ask questions and talk through what the diagnosis means.
- Provide information that people can take away with them and read over later (Emergence and Mind both have leaflets for service users about what the diagnosis means).
- People might not be able to take in information if they are upset about the diagnosis, so try to offer opportunities for further discussion at a later date.
- Acknowledge that not everyone agrees with the diagnosis and it is just one way to understand their difficulties.
- Remind people that they are no different now they have the diagnosis than they were before – being given a diagnosis doesn’t change who you are.
- Provide information about service user groups and organisations where they can meet other people with the same diagnosis if they want to (e.g. Emergence, STARS, online forums). For a list of resources see **Appendix 2**.

Learning points from **Chapter 2**

Personality disorder does not mean that someone cannot be treated, nor that they should be excluded from mental health services

- The way in which a person finds out about their diagnosis has an impact on their view of their future, but many people are not told about it and instead find out ‘accidentally’.
- How a person is given a diagnosis, and what happens afterwards, can make all the difference between someone feeling recognised and helped, or labelled and stigmatised.
- A diagnosis can be the key to unlocking a range of help and support, but it has also been used as a key to lock doors to keep people out of services.
- Whatever your role, you may be able to help a person to talk through how they feel about their diagnosis, and to access appropriate support and help.



3 How does personality disorder develop?

We have difficulty in agreeing what a personality disorder is, so it is even more difficult to be sure about its causes. In fact, rather than thinking in terms of causes, it makes more sense to think in terms of factors that make it more likely that a person will develop a personality disorder.

Most professionals agree that the most helpful approach to understanding the development of personality disorder is the **biopsychosocial model**. This is based on the idea that three types of factors interact to give rise to personality disorder:

- Biological sensitivities ('bio').
- Early childhood experiences with important others ('psycho').
- Broader social and environmental factors, including school, neighbourhood and culture ('social').

It is often thought that trauma and different types of abuse 'cause' personality disorder because these experiences figure prominently in the histories and narratives of people receiving help for personality disorder. However, it has become clearer from the results of community studies that some people suffer abuse and trauma and do not go on to develop personality disorder. It is also true that some people with personality disorder have not experienced significant abuse and trauma during childhood. Negative or adverse early experiences may be much more likely to give rise to negative consequences in a person who is biologically sensitive.

What is biological sensitivity?

This refers to characteristics of the individual's nervous system that are present at birth, and are usually genetically inherited. The human nervous system is not a machine that passively responds to inputs from the environment. The brain actively organizes incoming information in a way that substantially affects whether and how an event is experienced. Individuals vary in their brain's sensitivity and may attend to, select and register the same events very differently. For example, one person might feel devastated and rejected if they arrived for a doctor's appointment and found that the doctor had left already; for another, this might be experienced as a small irritation and a nuisance.

This is part of what we mean by differences in temperament, or basic personality predispositions. It is thought that about half of the variation between people in basic temperamental or personality characteristics is due to genetic differences. So that equivalent adverse life events can be experienced quite differently by different people.

For example, two twelve year old boys, **Liam** and **Danny**, both live alone with their mothers who have developed serious problems with alcohol. Liam who has an outgoing, easy temperament, notices when his mother is starting to drink to excess and keeps out of her way, staying late at school, and inviting himself to friends for sleepovers. Danny, who is much more shy, withdraws into himself, hides out in his bedroom playing computer games, and dreads seeing his mother out-of-control when she neglects herself and is verbally abusive to him.

Liam makes use of whatever good support he can find; Danny may be more likely to suffer long term harm from this difficult situation.

You may have observed the enormous temperamental variations that can occur in babies and young children from the same family. This is sometimes particularly evident in non-identical twins, who are likely to have had similar early experiences, but may be very different temperamentally. Research which follows children's development for several years has confirmed that children differ consistently in features such as their activity levels, their emotional reactivity, their alertness and their adaptability to change. These variations are almost certainly underpinned by biological differences in the brain.

Person-environment interactions

Understanding that babies and children have personality predispositions right from the start, we can see that the responses of caregivers will, at least partly, be determined by the behaviour of the infant. An infant who cries continuously, is difficult to soothe and sleeps irregularly will evoke a different parental response than a placid, cheerful baby who eats and sleeps predictably. The baby that is difficult to soothe may bring out more irritability or feelings of helplessness and unhappiness in the caregiver, than a baby who is easier to care for. There is then an element of an individual child influencing and shaping the environment, contributing to the creation of an environment that matches their personality, accentuating biological tendencies. However, this effect should not be overstated. Extreme environments can override any influence which the baby might have on shaping the caregiver's response. A caregiver who has serious problems and is abusive or neglectful towards a baby or child may behave in this way whatever the child is like. The main point is that personality does not develop from birth in a straight, predictable path, but is the outcome of interacting influences. People used to talk about what proportion of our make-up is determined by 'nature' and what proportion by 'nurture'. We now know that this is an oversimplification and that 'nature' and 'nurture' interact in complex ways.

Early experiences with important others

Nearly everyone agrees that early experiences in childhood play a large part in determining personality development and, therefore, personality disorder. The earlier the experience, the stronger the impact. For example, a child of ten who is regularly left unattended for several hours, may suffer less long-term harm than a small baby that is regularly left unattended for long periods.

Early experience can either accentuate or moderate biological predispositions. An infant with a tendency for high emotional reactivity can develop into a more or less reactive adult depending on the number and type of adverse events to which she is exposed and the type of caregiving provided; if she has a

soothing, responsive caregiver, and does not experience any unusual trauma in childhood, she may become a relatively calm child and adult; if she experiences neglect or abusive care, and/or a number of disturbing traumatic events, she may be prone to feel overwhelmed by extreme emotions.

Experiences that have a negative impact on personality can take the form of either isolated, 'one-off' events or long-term and pervasive experiences. For example, one person may be extremely traumatized and suffer long-term consequences from having witnessed one parent seriously injuring the other parent. For another person, it may be the effect of being repeatedly criticized and undermined by a parent that has a long-term impact on their personality; being repeatedly undermined over a long period may add up to have a major impact on someone's personality.

Severely adverse events and experiences strongly affect personality development because they provoke extreme anxiety which the child is not yet able to cope with. All types of emotional, physical and sexual abuse will have a strong impact on a child, and count as severely adverse events.

Children who are repeatedly treated in an abusive way may develop a dismissive attitude, making out that it does not harm them; we can think of this as their way of coping with something they cannot control. They, like any other child, will be hurt and harmed by abusive treatment.

The care that a child receives can also be a positive factor, helping them to learn to deal with emotional situations and to solve problems. Caregiving that is loving, reliable, consistent and attuned to the needs of the child will contribute to a personality type that can flexibly adapt to new situations, can effectively regulate emotion and is strong and resilient in the face of life's challenges. Caregiving that is unpredictable, inconsistent, hostile, neglectful and exploitative can engender a personality style that is anxious, avoidant, dependent and prone to reacting to problems in a way that can make them worse.

Core childhood needs

Much of our understanding of the link between early experience and adult personality derives from clinical observation of children and adults for whom psychological and emotional difficulties have arisen. On this basis, clinicians have suggested that children have a number of basic emotional needs. If these needs are not met, personality difficulties are likely to follow. The psychologist Jeffrey Young suggests that the core needs of the child are:



How does failure to meet core needs contribute to personality disorder?

It may seem common sense to us in our psychologically-oriented culture that a failure to meet the emotional needs of the child will lead to problems in adulthood. But human societies have not always seen it this way, historically or cross-culturally. For example, some groups of people think that strictness and physical punishment will produce well-behaved and obedient children; others think that this will produce angry and traumatised children.

If we are attempting to provide treatment and support to those with adult personality disorder, we need to understand more precisely what people have experienced that has shaped their personalities, and so leads to outwardly difficult-to-understand behaviour.

Therapists of different persuasions have attempted to provide explanations mainly of the difficulties associated with the diagnosis of borderline personality disorder.

All explanations of the development of personality disorder take as their starting point the importance of the relationship between an infant and a primary caregiver, usually a parent, which is often called the 'attachment relationship'.

Attachment theory

Attachment theory proposes that human babies come into the world all ready to form a strong attachment to a primary care giver during the first year of life. It is thought that becoming emotionally attached to the caregiver helps humans to survive and gives them an advantage. The closer the infant remains to the caregiver, the less likely he or she is to be vulnerable to threat or predation and the more likely the infant is to survive.

So infant behaviours such as crying or smiling are built-in to the way our brains work, and serve to keep the carer close at hand and to make the infant feel secure. This enables the child to learn through exploring the environment, confident that with the caregiver nearby, no harm will occur. When there is a threat of harm, the attachment system is activated and the infant communicates to the caregiver through crying or seeking closeness.

A responsive carer will protect the child by coming close and seeing what is wrong. An unavailable or insensitive care giver can leave the child feeling frightened, or confused. For example, the caregiver who responds to the child's anxious calls by becoming irritable with the child, may leave the child feeling that calling for a caregiver at times of stress only makes things worse, so that child may grow up avoiding close contact with others, particularly when they feel at their most vulnerable.

THE THEORY OF MENTALIZATION

Anthony Bateman and Peter Fonagy have extended attachment theory to try to explain the problems associated with borderline personality disorder: emotional, relationship and identity instability. They have coined the term ‘mentalization’ to refer to an individual’s capacity to think about and reflect on their own mental state (thoughts, emotions, action urges) and the mental states of others. They believe that this is vulnerable to disruption in people with borderline personality disorder, leading them to quickly become over-aroused, when they misinterpret the thoughts and feelings of others, and therefore experience extreme ups and downs in relationships.

Poorly established capacity for mentalization occurs when the attachment relationship has been inadequate to the child’s needs. A carer who bursts into tears when they see the baby crying will offer no comfort; the carer who expresses concern through her eyes and her tone of voice, shows that she knows the baby is upset, but is not so upset herself that she is overwhelmed. The child takes this experience of a responsive carer into him or herself and can later in life become a good ‘carer’ to him or herself. This gradually enables the child to manage their own emotions and to experience inner stability.

Where the caregiver is unavailable, preoccupied or incapable of responding sensitively and accurately, the child will internalize a response which does not match his feeling. For example, if the carer laughs mockingly when the child cries, the child will internalize a sense of an uncaring or dismissive ‘carer’. If there is no internalized ‘in tune’ carer, the infant will continue to feel anxious or upset, and, because the carer has not been able to soothe his anxiety, the anxiety may have a quality of being impossible to think about or moderate. It feels like something in the mind which does not quite belong to the self. This can lead to an urge to get rid of the experience. People who act impulsively or who self harm, often describe these behaviours as a way of trying to get rid of an internal feeling of tension that they cannot understand, can’t change, and can’t bear. The child and the adult may then lack resilience in the face of life stress, and can be vulnerable to emotional collapse when, as often happens, further trauma occurs.

Broader social and environmental factors

There are a range of factors that will contribute to the development of personality disorder and these factors also interact with each other, so that there can be a circular quality to the process. A child who has been disturbed by traumatic experiences or poor care, may have difficulty controlling his own behaviour or emotions, and then be seen as ‘difficult’ or ‘demanding’, and so evoke a negative reaction from some teachers or family members. The social and cultural environment of the extended family, schools, peer group, and community or religious groups, also play a part, either for better or for worse. We know that one good relationship with someone like a grandparent or teacher can do a great deal to offset the bad effects of a difficult home life.

Inequality, whether this be in terms of poverty, access to good schools and housing or social prejudice, can have a major impact on people’s lives.

Our society values the acquisition of wealth, and those who do not achieve this may feel that they have failed. We are also a competitive society. During childhood, the testing and grading of children at school creates winners and losers. We are also status conscious. Social prejudice, on the grounds of race, gender, sexual orientation, religion (and other characteristics), despite our best efforts, continues to be a powerful force. For some unfortunate individuals, biological sensitivity, adverse early experience and social marginalization line up to create a life course that leads to personality disorder.

Life course of personality disorder

It was once thought that people with personality disorder were unlikely to recover. More recent research, following up people with borderline and antisocial personality disorder, suggests that there is a substantial amount of positive change over time. The change occurs particularly in the area of impulsive behaviour and emotional instability. It is likely that this change is due to maturation. Over time, people become more able to predict the consequences of their actions, learn how to regulate their emotions and become more accepting of themselves.

However, it is still worth trying to help people with personality disorders. Without help, people can suffer for years and even decades, and their problems are likely to impact on the lives of those around them. Even though someone's personality may mature, their core dispositions appear to remain the same and may continue to create difficulties for them. Difficulties in relationships and a subjective sense of distress and dissatisfaction are likely to continue even if the person is less impulsive and emotionally unstable.

Recovery, or discovery?

In mental health services, the idea of 'recovery' has become very fashionable, with 'recovery programmes' and 'recovery teams' in some places. The recovery model is intended to counter pessimism about whether people can change, and to stress the possibility of someone being able to return to normal functioning and re-engagement with society. This idea has been developed with people with major mental illnesses. However, in the field of personality disorder, people have questioned the usefulness of this model. If someone has very longstanding problems they may never have experienced a level of 'wellness' that they want to return to. Members of Emergence, a user led organisation for personality disorder, (Turner et al 2011) argue that the recovery model stresses people fitting in with society and engaging with the outside world, playing by its rules – that is, achieving 'social inclusion'. For some people, this has been so traumatic in the past that this is not a path they want to follow. For example, they may prefer instead to turn to their inner world, perhaps pursuing creativity rather than fitting in. Turner et al suggest that the journey of someone with a personality disorder be thought of as 'self discovery' rather than 'recovery'.

Learning points from **Chapter 3**

The child or baby will be affected by poor quality or abusive care, but the child's temperament may also affect the way they are treated by others.

- Experiences in childhood which are harmful may take the form of extreme and traumatic events, or more apparently low-key negative experiences repeated regularly over a long period of time.
- Different cultures and at different times in history people have had different ideas about the best way to treat children. From observing the lives of people with personality disorder, we now have a clearer idea of the kinds of experiences that can be harmful, and the kinds of things that help children to develop flexible, resilient personalities.
- Having a caregiver in childhood who attended to and thought about what we were feeling and experiencing, helps us to develop a reliable ability to think about our own emotions and those of others.
- For some people, biological vulnerability, experiences in relation to caregivers, trauma and social disadvantage, add up to create a path towards personality disorder.
- Good experiences in childhood in relation to key figures – teachers, parents, grandparents – can do a lot to build good attachment patterns and resilience.
- Someone who has had lifelong problems may not be looking to 'recover' their previous functioning, but will be wanting to explore new ways of being, 'discovery' not 'recovery'.

"it's how somebody
treats you,
the authenticity
of the relationship



That
really matters."

4 What can I do to make a difference?

Providing therapy or counselling may not be part of your role, but every interaction with a service user that you have may be therapeutic. Social care, or personal care, or housing support, which is provided in a curious and compassionate way, may help a service user to feel cared for, hopeful and empowered rather than feeling frustrated, misunderstood and despairing.

RECEIVING GOOD CARE, IN WHATEVER SITUATION, CAN BE A TURNING POINT IN A PERSON'S LIFE.

It is very important, when working with a person with personality disorder, to be clear about what your 'primary task' is. The primary task is what you are being employed to achieve by your organisation. If you are a housing support worker, your primary task may be to help the service user to obtain and maintain a housing tenancy. If you are a social worker in a children's social care team, your primary task is to reduce the risk of harm to children in the family. If you are a worker in a community mental health team your primary task may be to help the service user to reduce their vulnerability to crises.

Whatever your primary task, it can be more difficult to achieve when the service user has a personality disorder. Their anxieties about relationships may make it difficult to engage them with the primary task. Their problems in managing their behaviour are likely to affect the professional relationship.

A worker needs additional capabilities, above and beyond the core capabilities required for the primary task. These additional capabilities centre on the relationship between service user and worker. This needs to be one in which both parties recognise, openly acknowledge and support the development of **personal agency** for the service user. Personal agency means that the service user takes responsibility for their actions but in a context which is non-blaming, non-judgmental, and compassionate towards the difficulties they have in doing this.

How can personal agency be developed and supported?

The most effective forms of therapy for people with personality disorder all tackle this issue of personal agency, so we can learn from them how to develop and support it.

It helps to be explicit about the primary task and clearly define how you will both know when this has been achieved. This prevents a 'drift' in the direction of general support (although occasionally providing general support may actually be the primary task, particularly during transitions or life-events).

It is also very important to try to carefully position yourself in the relationship so that you are neither overly supportive nor overly demanding – expecting the service user to demonstrate more independence and competence than they are capable of at that point in time. Sometimes we call this being **not too close and not too distant**.

An overly supportive relationship (doing a lot for the service user) undermines autonomy, does not help to develop personal agency and risks encouraging dependence. It may also invite an overly strong attachment to the worker, leading to very intense emotions which get in the way of the primary task. An overly demanding relationship, on the other hand, is likely to lead to hostility or disengagement because the service user feels that the worker does not understand how hard it is for them to do what is being expected. So we need to occupy the middle ground between these two extremes.

Another way of thinking about this is in terms of professional boundaries. We want to establish a relationship that is warm, friendly, compassionate and non-judgmental. At the same time, the relationship has a purpose and a time-frame, which is the achievement of the primary task within a defined period of time.

MIGHT HELP TO FOSTER 'PERSONAL AGENCY'	MIGHT INTERFERE WITH THE DEVELOPMENT OF THE SERVICE USER'S PERSONAL AGENCY
<ul style="list-style-type: none"> • What help do you need to do this yourself? • At what point do you get stuck filling in this form? So why don't you do it up to that point and then I can help you think what to put for that question. • I don't know any more about this than you. Is it worth looking on the internet? • I wonder whether you are more capable than you think you are. I remember when you did X and you felt you'd handled it very well. • Is there something specific about this situation that makes you feel you won't be able to do it? Is there a way round that? 	<ul style="list-style-type: none"> • Leave it with me – I'll sort it out for you. • Is there someone you can ask to do this for you? • I was planning to take leave that day but if you really need me to go with you I could always cancel that. • You may not feel like doing it but sometimes you have to make yourself do things you don't want to. • You can't go on expecting other people to do that for you – It's time you did it yourself.

“I was in the preparation group for about a year, but it probably took at least six months of overdosing, self abuse, neglect and some major tantrums at staff before I was able to see that my care and more importantly my recovery is MY responsibility and it's not up to the staff or my family to make everything better, only I can. I'm sure it was at that point that I was then able to start to take control of my recovery and move forward.”

What might get in the way of achieving a boundaried relationship?

Often what gets in the way of achieving a boundaried relationship is strong emotion and challenging behaviour on the part of both the service user and the worker. We know that people who may attract a diagnosis of personality disorder have difficulties with their emotions, their behaviour and their relationships. This is bound to emerge in the relationship with the worker. The direct expression of strong emotion may evoke the same in the worker. If a service user gets very angry with a worker, maybe because they have not responded to a request, this may make the worker feel very anxious and lead to him/her reacting by trying to calm the anger but in doing so the worker may risk doing too much for the service user in a way that interferes with the development of personal agency. Conversely, the worker may get angry and behave accordingly, so that the service user feels misunderstood and rejected.

HOW CAN WE DEAL WITH OUR OWN AND OTHERS' INTENSE EXPRESSIONS OF EMOTION?

In order not to get caught up and overwhelmed by intense feelings that the service user may have, it helps to be **aware** that they have strong feelings, and to **'step back' a bit**. Allowing a slight psychological distance, makes it less likely that we will react thoughtlessly. It also enables us to **identify the emotion** and put words to it. If you can't tell exactly what the person is feeling, it helps to at least acknowledge that they are feeling very stirred up or upset.

We need to identify our own emotions privately to ourselves – it is not usually helpful to tell the service user how their behaviour makes you feel, but sometimes how we feel is a clue to how they are feeling. If you start to feel very frustrated with them, for example, it may be that they are feeling very frustrated with you or the situation they are in. We need to help the service user to identify their feelings in an open and explicit way. This can best be achieved by adopting an attitude of **curiosity** about the service user's emotions. If we talk with certainty ('you are very angry') this risks sounding patronizing and overbearing. Saying 'Something about this situation has really got to you' or 'We all feel angry when things don't work out the way we want' is less judgmental and more comradely.

COMMENTS THAT MAY HELP RESTORE COMMUNICATION	COMMENTS THAT MAY MAKE THINGS WORSE WHEN SOMEONE IS ANGRY
<ul style="list-style-type: none"> • Something about this situation has really upset you. • Can we think together what it is that has upset you so much. • I'm sorry – I realize that would have been upsetting for you. • I realize this is very frustrating for you but can we think together about how to try and sort it out, and how to avoid this happening again. • I get the sense you are feeling under tremendous pressure – is that right? 	<ul style="list-style-type: none"> • You can't always get what you want. • You know there is nothing I can do about this. • Calm down. • I'm not going to speak to you while you are shouting at me. • We've been here before and my answer is the same as it was last time: I can't do that. • Your behaviour is starting to make me very angry.

How can we deal with challenging behaviour?

Challenging behaviour in the service user, usually in the form of self-harm or aggression, is a problem for the worker because it makes them feel anxious or angry, and therefore less able to respond in the interests of the service user. It's a problem for the service user because it can invite rejection from the worker. It is also often regretted afterwards, and it can get in the way of someone learning about themselves and how to deal with their feelings constructively – with 'emotional growth'.

It helps if there is clarity about what the consequences are if these challenging behaviours occur. This should be made explicit in the service's operational policy. For example, the service might have an explicit policy that verbal abuse of reception staff will not be tolerated, or that anyone cutting in the building will be sent to A&E.

But these boundaries need to sit alongside an acknowledgement that challenging behaviour serves a function, either emotionally for the service user, or in the relationship between worker and service user, and that the person needs help to manage these impulses in a different way. Sometimes one of the primary tasks of a service will be to address these challenging behaviours with the service user and to think together about what has triggered the behaviour, what the service user is thinking and feeling at that moment, and whether there is a different way of dealing with these thoughts and feelings or with similar situations.

Self harm

'Self harm' is when someone damages or injures his or her own body on purpose. There are many forms of self harm including:

- Cutting, biting, burning or picking at the skin.

- Taking overdoses of medication.
- Deliberately not taking prescribed medication.
- Misusing drugs or alcohol.
- Hitting or punching oneself, or head-banging.
- Engaging in risky sexual behaviours like unprotected sex with strangers.
- Deliberately starving oneself or binge eating.
- Deliberately consuming substances that are poisonous or cause disgust or illness.

Self-harm and suicide usually have different intentions; if someone is self-harming they do not usually intend to kill themselves, though sometimes the behaviour can result in accidental death. In fact, many people use self-harm as a coping strategy to stop themselves committing suicide. Regardless of the injury or degree of harm it is helpful to find out what the person intended, rather than make assumptions.

THERE ARE MANY REASONS WHY PEOPLE SELF-HARM; HERE IS A SMALL SAMPLE OF EXPLANATIONS:

- To get bad feelings ‘out’ of the body (through bleeding or vomiting, for example).
- To help the person feel in control if they are struggling with feeling trapped, desperate and powerless, or out of control.
- To give a concrete form to emotional pain.
- To make the person feel alive when they feel ‘dead’ or numb.
- To relieve the tension of lots of pent up emotion, like anger or hurt.
- To engage people’s concern or to provoke a response.
- To bring the person into the present when they feel lost in bad memories of the past.
- To protest about how they are being treated.
- To punish him or herself, or others.

“When I was self-harming or suicidal, although I may not have realised it at that time, it was a call for help. I just wanted someone to care for me and love me and not to treat me like I was trouble and meaningless. When people used to say I was ‘attention seeking’ they used to say it like I was being bad but I was attention seeking because no-one ever paid me any attention or cared for me.”

You can see that it would be a mistake to put forward any one reason why people self-harm. There are many reasons and sometimes more than one reason will be operating at once. The important message is to be curious about what has led a particular individual to do this at this particular time.

Responding to self harm

One of the things that gets in the way of workers responding compassionately to someone who has self-harmed is that it can make us feel **angry** that someone has done this to themselves, particularly when it may be our job to treat people who have suffered through accidents or illness. The person who harms themselves seems to be making our job more difficult. But they are suffering too. No-one does this to themselves if they feel they can express themselves or get what they need in other ways.

Self-harm may also make us feel **disgust**, particularly when someone has done something extreme. They may be very cut off from their feelings and feeling very little at that moment, but we feel the shock of the injury they have inflicted. It can sometimes feel like an assault on our own body.

At times someone self-harming can leave staff feeling very **anxious**. We feel frightened that the injury is life-threatening, or that it signals that the person is at risk of suicide, or we are not sure what they may do next.

In all these situations, staff need to support each other to talk through these feelings, so that they can help the service user by being **curious, concerned and practical**:

- Assess the risk associated with the injury and respond accordingly (for example, do they need an ambulance, or do they have a wound that needs suturing?)
- What needs to be done now to make the person safe? (Do they still have pills or instruments that could be used to harm themselves further?)
- Is it possible to understand what triggered this behaviour on this particular occasion?
- Has the situation that triggered this been resolved or are they still at risk?

When the immediate situation has been dealt with, you might think with the service user about:

- Is it possible to understand more about what leads them to self-harm?
- Is there a risk management plan in place and does everyone (including the service user) know what it is?

The NICE Guideline on Self Harm (2004) has specific advice on good practice for people working in primary care, emergency departments, in secondary mental health services, and with older people as well as children and young people.
www.nice.org.uk/cg16

The Royal College of Psychiatrists also provide guidance for staff from all settings, in responding effectively to self harm.
www.rcpsych.ac.uk/healthadvice/problemsdisorders/self-harm.aspx

“I remember being on the ward and having a dressing put on a wound that I had caused myself. Although everyone was very professional and were treating it properly I think I wanted someone to ask me about it: to ask me why I did it. I wonder if they were afraid of what I might say.”



HELPFUL THINGS TO CONSIDER IF SOMEONE HAS SELF-HARMED	APPROACHES THAT MAY BE UNHELPFUL
<ul style="list-style-type: none"> • Ask the individual if they know what would be helpful to them at that moment – but don't assume that they will be able to tell you. They may not know. • Try not to appear overwhelmed by the injury, but at the same time do not ignore or shut off your own emotional response. If you do, you may come across as cold and uncaring. • Even if the person does not appear to be emotional, it may be helpful to acknowledge that they may feel very upset or stirred up. • If you need to touch the person to treat an injury, remember that they may have a history of being abused or assaulted; explain what you are doing and why. • Ask whether there is a friend or someone they would like to have with them while receiving physical treatment. 	<ul style="list-style-type: none"> • Avoid saying things which reinforce a sense of shame and failure like, "oh but you were doing so well", "It's been so long I thought you'd stopped doing that". • Avoid seeing this as not a real problem – "We've got people here with real injuries to deal with you know". • Avoid implying that the service user has done this by choice to 'get attention'. • If you have a negative emotional reaction to someone who has self-harmed, but don't step back and reflect on this, you may subtly communicate your negative feelings to them and risk making them feel worse.

"I couldn't understand my behaviour and why I reacted like I did and the most helpful thing for me was when I was able to explore where that behaviour started and why I acted in those ways."

Practical suggestions for helpful ways to respond to someone who has self harmed

Evidence suggests that the attitudes and behaviour of staff towards people who self harm is the most significant factor affecting their experience of care. In thinking about dealing with challenging behaviour we have explored why it can be so difficult to respond well; an empathic and non-judgemental approach is crucial.

There are different approaches to helping people who self-harm frequently:

HARM MINIMISATION

One view is that trying to make people stop self-harming by reducing access to harmful objects can actually make injuries worse. Many people who self-harm do so regularly and have a routine to their behaviour which keeps risk at a level they are familiar with. If people's usual methods are removed, they can resort to other, more dangerous methods of self-harm. Working with people to support them to minimise risk, and explore alternative coping strategies and distraction techniques may be more helpful. If we understand that self-harm serves an emotional function, exploring alternative ways for that function to be met is crucial to reducing self-harm.

ALTERNATIVE APPROACHES TO SELF HARM

Some therapies, such as DBT, collaboratively establish with the service user how to work with them to reduce the likelihood that they will have urges to self-harm, and explore alternative strategies to coping with any urges, and managing difficult emotions. This may also involve agreeing how to limit access to the means of self-harming (tablets, blades, etc).

Learning points from **Chapter 4**

Be clear about what the purpose of your meetings with the service user is: the primary task.

- Whatever your primary task, your relationship needs to support the service user's personal agency; this can best be achieved by establishing a relationship that occupies the middle ground between support and demand.
- The management of high levels of emotion requires awareness, identification and naming.
- You and your service user need to be clear about the limits of your tolerance of challenging behaviour. Always remember that challenging behaviour serves an emotional and interpersonal function. Your service user may need help to do things differently.
- When someone has self-harmed, attending to any immediate dangers from injury or self-poisoning should be a first step.
- The person may not always know why they have self-harmed, but being curious and concerned, and attending to their physical health needs with sensitivity is always helpful; think with them how to find alternative coping strategies.

"Getting the right help
and support
made the difference to me
between surviving,
and thriving."



5 What help might be available?

How do we know when someone needs help? People with the problems of personality disorder may first present as needing help in a range of places.

Here are some examples of places people may first present:

- At the GP with physical symptoms. People with personality disorder often have significant physical health problems. People can also experience physical symptoms, which, on thorough investigation, do not have any obvious medical explanation.
- To drug and alcohol services.
- In the criminal justice system with convictions for repeated crimes such as theft or assault.
- Being homeless and sleeping rough.
- To mental health services.
- To A&E with repeated self-harm.
- To eating disorder services with anorexia or bulimia, or obesity that poses a threat to health.
- Through a social services safeguarding alert for lack of self-care or vulnerability to exploitation.
- To friends when in crisis, who then recognise that there is some underlying problem.
- People finding out about it for themselves on the internet.

In any of these situations, an interview with a worker who has a basic awareness of personality disorder should raise the question for the worker of whether the person has personality difficulties that are contributing to their other problems, and if so, how they can be helped.

Most people with personality disorders will never access specialist help, but will rely on support from friends, relatives, their GP, and other agencies such as religious organisations, voluntary agencies, or social services. But people with severe problems associated with personality disorder require timely and effective help, possibly from a range of agencies.

The services available will vary from one area to another. It is a good idea to find out what is available in your locality, and how you can help people to access different kinds of help. Not everyone wants to be seen by doctors or professionals; many people prefer self-help or voluntary agencies and for others a combination is helpful. It is important therefore to take into account what the person has tried already, what appeals to them, and whether there are forms of help that they want to avoid.

What might be available?

1) SELF-HELP, VOLUNTARY AGENCIES AND SOCIAL SUPPORT

Voluntary sector organisations and self help resources can be key to enabling people to build resilience and reduce isolation. It is often helpful to gather together information about a range of resources for people to be able to choose what they feel might be helpful to them at any one time. This might include:

- Websites, online forums, and phone lines can provide both information and support. A list of useful websites is in **Appendix 2**.
- Details of voluntary sector organisations in your area which offer support and information. Although there are only a few which focus on personality disorder, many offer support and activities regardless of diagnosis. These can be often be found at your local Community Voluntary Sector Centre, local service user group, within mental health NHS Trust websites or through a simple online search.

- Peer support/social activities. Spending time with others who share similar experiences can be immensely powerful in generating hope, learning new coping strategies and making connections with others. The availability of peer support varies across the country, but your local mental health Trust or service user group might be able to signpost you to a group/organisation.
- Books. For many who struggle with being among other people, books provide an ideal way of finding out more about the diagnosis, reading of other people's experience, developing self understanding and new coping strategies. A list of useful literature is available in **Appendix 2**.
- Wellness Recovery Action Plan (WRAP). This is an international resource to support people to think through and develop personal resources and tools which can be used in situations which the individual finds difficult. It is designed by people with lived experience of mental distress and there is now also a WRAP app available. More information is available at: www.mentalhealthrecovery.com

2) LOCAL MENTAL HEALTH SERVICES

Improving Access to Psychological Therapies (IAPT)

The most easily available and least intensive form of help for mental health problems is the short-term therapies provided within IAPT services. These interventions may be for a very short period of time (4-6 weeks), or medium term (16-20 weeks), depending on the severity of the problems. They are usually fairly practical interventions designed to treat anxiety and depression. They are available through self-referral or referral by a GP. Some people with personality disorders may benefit from this type of help, if they are experiencing anxiety and/or depression and their personality difficulties are not too severe. For others, particularly those who have difficulties in relationships, such short-term treatments may be unhelpful. Short-term treatments are very unlikely to help the person to change their underlying personality difficulties, but may well bring to the surface very difficult issues without the space to safely explore these. As a result, treatments of 3 months or less are not recommended by the NICE guidelines for people with borderline personality disorder. It is advisable for anyone with more severe personality difficulties to seek help at the next level up, from secondary mental health services.

Secondary mental health services

Access to these services almost always requires a referral by the person's GP. Some mental health services have a specific team working with people with complex needs or personality disorders; in other areas, generic teams may work with people with a range of different problems, but within the team there will usually be workers with special expertise in personality disorder.

When someone first has contact with a mental health team, the first step will usually be an initial appointment or assessment, when the worker, who may be a mental health nurse, a psychologist, a social worker or a psychiatrist, tries to get a picture of the person's difficulties including their childhood history, the history of the problems and what help has already been tried. They may draw on information from relatives, friends or carers, or they may use some structured measures like standardised interviews or questionnaires to add to this picture. This information is put together so as to allow a care plan to be collaboratively developed with the service user.

Some teams will put quite a lot of emphasis on arriving at a diagnosis (see **Chapter 2 ‘Why is the diagnosis so controversial?’**), while others will put more emphasis on arriving at a plan with the service user about what the issues are that they need help with. If the service user is unhappy about the way they are being described or treated, it is usually helpful to speak up and to try and have a conversation about their concerns.

Structured clinical management, or structured clinical care

Current best practice in relation to standard care for someone with complex needs or personality disorder is ‘structured clinical management’ or ‘structured clinical care’. This is different from some traditional mental health care approaches. It is structured, involves regular agreed appointments, is time-limited (even though possibly of long duration) and seeks to establish agreement with the service user about what they would like to get out of their care. This would include thinking about how they

would like their life to be, what problems need to be resolved to achieve this, and how to approach solving these problems. It treats the service user as an active and responsible participant in their care, not as a passive recipient and is, therefore, very much a collaborative, shared enterprise. It may involve some motivational work, and some help in managing intense emotions and impulsive behaviour. Sometimes service users attend problem solving groups as well as one to one appointments.

The care plan should always include a crisis plan so that if the person experiences a worsening of their problems, they and other people involved in their care, have an agreement about how to manage this, and where they should turn for help if they can’t manage on their own.

For many service users, structured clinical care provides an effective way to meet their needs and support their progress at a comfortable pace. For other people, more intensive treatment might be needed and specific psychological therapies may be considered.

3) SPECIALIST PSYCHOLOGICAL THERAPIES FOR PERSONALITY DISORDER.

Psychological therapies or ‘talking therapies’ for personality disorder all share some common elements:

- **Recognizing the influence of the past on the present.** The therapy will take into account the individual’s history, their experience of close relationships in early childhood, the patterns of relating which they have established, and the impact on them of any trauma they have experienced, particularly when growing up.
- **Acknowledging and working with difficulties in engagement.** Someone who struggles with forming or sustaining relationships, or who often feels hurt, threatened or misunderstood in relationships, will often find it difficult to make a relationship with a person who is trying to help them. The worker will need to be compassionate and have an understanding of the service user’s anxieties about seeking help and to be able to work with the conflicting feelings which the person has about seeking help.

Many people want help, yet also fear getting involved or dependent, and this may lead them to feel hostile towards someone who is offering help. The worker needs to be able to understand what lies behind apparent reactions of hostility or lack of interest on the part of the service user. Workers will also need to have the skill to work constructively with a service user when something seems to have gone wrong or the person disengages from the therapy or the service.

- **Knowledge of self and other.** Staff working with people with personality disorders need to be good at understanding others, but also need to have a good knowledge of themselves. People with personality disorders are often very sensitive to the way others treat them, and workers need to be aware of how they, the worker, comes across and the impact they have on others.

“I knew I needed help, I asked for help but when I got a social worker I didn’t trust them to be able to understand or care about me. For a long time I was testing her to see how she responded and even after that went through phases of drawing her in and pushing her away. My whole life experience up ‘til then had taught me that other people couldn’t cope with my emotions and getting close to someone would cause me pain. My behaviour exasperated my social worker so much, she did what I had always expected her to and handed me over to someone else in the team, with a warning that I was difficult, i.e. she left.”

- **Helping people shift from action to thought.** People with personality disorders may at times resort to action when they cannot bear to think about their feelings, or don’t know what to do with their feelings. This may be particularly true of people with more ‘impulsive’ personality disorders like borderline or antisocial personality disorder. Someone who feels they have been shown up and humiliated may become very angry or violent; someone who feels very pent up and distressed may harm themselves because they don’t know what else to do, and they find that self-harm gives a feeling of release or relief. Psychological therapies for people with personality disorders usually include ways of helping the person to think about, and speak about their feelings, rather than expressing them through actions.
- **Understanding and managing transitions, endings and loss.** If someone has a history of being rejected or abandoned, or feeling unsafe in relationships, he or she may find endings of relationships particularly difficult. Any therapy for people with personality disorders will not only help people to cope with endings or losses they are facing or have experienced in their lives, but should also pay attention to how the service user will manage the end of the contact. With good quality psychological therapies, the ending of the therapy is planned in advance, the therapy is often longer than for other types of problems, and the therapist will pay attention to the range of feelings which the client has about ending, and where they will obtain support after the therapy has finished.

Specific psychological therapies that may be helpful

There are a number of psychological therapies which have been shown in research trials to help people with personality disorders. Almost all of this research has been done with people with borderline personality disorder. There is very little research on treatments for other forms of personality disorder, which does not mean that they cannot be treated, it just means that we have to rely on ‘practice-based evidence’ – that is, the experience of practitioners and clinicians in knowing what is likely to be helpful. The therapies outlined in **Appendix 1** can be offered by a range of professionals with different trainings – psychiatrists, psychologists, nurses, psychotherapists and others – but usually they will have had some specialist training in the particular form of therapy. Sometimes someone may be offered therapy that is not the exact therapy described in this guide, but is a variation of one of these therapies.

There are also many other types of psychological therapy, beyond those listed here. In particular, there are newer treatments which do not yet have an evidence base but may still be helpful.

A brief description of the psychological therapies that may be available is included in **Appendix 1**.

A service user will not always be ready to use therapy that is offered at the point when it is first made available. Establishing a good working relationship with the service user, and providing them with a good experience of engagement, will provide the best foundation for any treatment. Building trust, confidence and optimism for change can be crucial foundation stones, especially for someone who has had few good experiences of engaging with other people in caring roles, or with professionals. Building these foundations for constructive engagement and development is something that everyone can contribute to. The Enabling Environments initiative can help to create a culture within an organisation where service users can start to feel listened to, respected, and eventually, safe.

4) THERAPEUTIC ENVIRONMENTS

It is likely that the ‘atmosphere’ or ‘culture’ of a service has an impact on whether people engage and stay, or feel out-of-place and leave. Words which describe a helpful culture in ordinary language are: welcoming, warm, informal, friendly, safe, open, easy-going, belonging, non-judgemental, humane – and not: stuffy, stiff, strict, harsh, bureaucratic, secretive, scary, intimidating or rigid.

The Royal College of Psychiatrists Centre for Quality Improvement has defined the values base for a healthy psychosocial environment in a project called ‘Enabling Environments’ (see www.enablingenvironments.com). The Enabling Environments Award is a quality mark given to services that can demonstrate they are achieving an outstanding level of best practice in creating and sustaining a positive and effective social environment. It would be good if all organizations providing health and social care became ‘Enabling Environments’.

ENABLING ENVIRONMENTS ARE:

- Places where positive relationships promote well-being for all participants.
- Places where people experience a sense of belonging.
- Places where all people involved contribute to the growth and well-being of others.
- Places where people can learn new ways of relating.
- Places that recognise and respect the contributions of all parties in helping relationships.

How well would your organisation rate on these criteria?
Would you be in a position to apply for this award?

The Enabling Environments Award is based on core values that contribute to healthy relationships. **The values are:**

- 1) BELONGING** – The nature and quality of relationships are of primary importance.
- 2) BOUNDARIES** – There are expectations of behaviour and processes to maintain and review them.
- 3) COMMUNICATION** – It is recognised that people communicate in different ways.
- 4) DEVELOPMENT** – There are opportunities to be spontaneous and try new things.
- 5) INVOLVEMENT** – Everyone shares responsibility for the environment.
- 6) SAFETY** – Support is available for everyone.
- 7) STRUCTURE** – Engagement and purposeful activity is actively encouraged.
- 8) EMPOWERMENT** – Power and authority are open to discussion.
- 9) LEADERSHIP** – Leadership takes responsibility for the environment being enabling.
- 10) OPENNESS** – External relationships are sought and valued.

You can see similarities between these values and the ‘core childhood needs’ proposed by Jeffrey Young and described in **Chapter 3** – the need for secure attachment to others (safety, belonging, involvement), autonomy (communication, empowerment), spontaneity and play (development, openness), and realistic limits and self-control (boundaries, structure). It looks as though those experiences that foster healthy development in children have adult equivalents that foster healthy organisations – organisations that encourage the development of their service users and their staff.

There is more about the characteristics of healthy organisations in **Chapter 7**.

What do the NICE guidelines advise?

‘NICE’ Guidelines⁴ have been developed for common conditions treated within the NHS, to summarise the research evidence and to recommend best practice in treating different conditions. So far NICE Guidelines have only been produced for two personality disorders,

⁴ National Institute for Clinical Excellence (‘NICE’) Guidelines (Clinical Guideline 77 on Antisocial personality Disorder, 2009; Clinical Guideline 78 on Borderline Personality Disorder, 2009)

borderline and antisocial personality disorder which are the most commonly recognised personality disorders.

BORDERLINE PERSONALITY DISORDER

NICE reviewed all the published evidence for treatment of Borderline Personality Disorder and produced guidelines in 2009. The overall result of the literature search was that there was not enough evidence yet to be able to say definitely what treatment or treatments should be offered for borderline personality disorder, although some looked promising. It confirmed the government's position that 'personality disorder IS treatable' and made suggestions for further research.

Here are some of the points raised by NICE as relevant to practitioners working with borderline personality disorder:

- Explore treatment options in an atmosphere of hope and optimism, explaining that **recovery is possible and attainable**.
- Build a **trusting relationship**, work in an open, engaging and non-judgemental manner, and be consistent and reliable.
- Bear in mind that **many people will have**

experienced rejection, abuse and trauma, and encountered stigma.

- **Do not use brief psychological interventions** of less than 3 months duration.
- **Drug treatment should not be used** specifically for borderline personality disorder or for the individual symptoms or behaviour associated with the disorder.
- **Work in partnership** with people with borderline personality disorder to develop their autonomy and promote choice.
- Fears of abandonment and previous experiences of unsatisfactory endings mean that many people with borderline personality disorder find the **ending of treatment** or discharge from a service especially challenging.
- Specialist services should not be restrictive and should offer **more than one type of intervention** to meet the predominantly complex needs of service users and allow for flexibility and choice.

CARE PLANS

Here are recommendations from the NICE Guideline for how suitable care plans should be developed:

Develop comprehensive multidisciplinary care plans in collaboration with the service user (and their family or carers, where agreed with the person). The care plan should:

- Identify clearly the roles and responsibilities of all health and social care professionals involved.
- Identify manageable short-term treatment aims and specify steps that the person and others might take to achieve them.
- Identify long-term goals, including those relating to employment and occupation, that the person would like to achieve, which should underpin the overall long-term treatment strategy; these goals should be realistic, and linked to the short-term treatment aims.
- Develop a crisis plan that identifies potential triggers that could lead to a crisis, specifies self-management strategies likely to be effective and establishes how to access services (including a list of support numbers for out-of-hours teams and crisis teams) when self-management strategies alone are not enough.
- Be shared with the GP and the service user.

ANTISOCIAL PERSONALITY DISORDER

Antisocial personality disorder is often linked in people's minds with criminal behaviour, and around 50% of people in prisons might meet criteria for antisocial personality disorder; however, only 47% of the people who meet criteria for antisocial personality have significant arrest records (NICE CG77, 2009).

The companion guide to this one, 'Working with Offenders with Personality Disorders in the Community' (Ministry of Justice, 2011; www.justice.gov.uk) contains a great deal of helpful information and advice about working with offenders with personality disorders, whether this is antisocial or other personality disorders.

Whether or not someone with antisocial personality disorder has a criminal record, all people with antisocial personality disorder have mental health needs, and antisocial personality disorder is often co-morbid with depression, anxiety and alcohol and drug use.

The NICE guideline for antisocial personality disorder (ASPD) spells out some recommendations for good practice:

- People with ASPD tend to be excluded from services and **staff should work actively to engage them.**
- **Positive and reinforcing approaches** to treatment are more likely to be helpful than those that are negative or punitive.
- **Work in partnership with people with ASPD** in order to develop their autonomy by encouraging them to be actively involved in finding solutions to their problems, even when in crisis, and encouraging them to consider different treatment options or life choices available to them, and the consequences of choices that they make.
- Provision of services for people with ASPD often involves significant inter-agency working. Pathways between services should be clear, and **communication between organisations should be effective.**
- **Pharmacological interventions (drug treatments) should not be routinely used** for the treatment of antisocial personality disorder or associated behaviours of


aggression, anger and impulsivity. Pharmacological interventions for comorbid mental disorders, in particular depression and anxiety, should be in line with recommendations in the relevant NICE clinical guideline.

As yet there is limited evidence about effective treatments for antisocial personality disorder. This does not mean that 'nothing works', only that this group are less easily studied than, say, people with anxiety symptoms or depression, and interventions have tended to focus on reducing criminal behaviour rather than treating the underlying personality difficulties. NICE recommend group based cognitive and behavioural interventions focused on reducing offending and other antisocial behaviour, and to address problems such as impulsivity and interpersonal difficulties. As more research is conducted on helpful treatments for people with personality disorder, it may well be that the recommendations for effective treatments for people with ASPD will broaden to include a wider range of treatment options.

Learning points from **Chapter 5**

Someone who struggles with forming and sustaining relationships will find it difficult to make a relationship with a person who is trying to help them, so the worker will need an understanding of the service user's anxieties about seeking help.

- It's helpful to know what services are available in your locality for people with personality disorder.
- Talk to the service user about what sort of help they would prefer – some people prefer to get help from voluntary agencies or online resources, whereas others may want professional or specialist help.
- Medication is not recommended for the treatment of the two most common personality disorders, antisocial and borderline personality disorder, but it may be useful to treat symptoms such as depression or anxiety which are associated with the personality disorder or related disorders.
- All psychological therapies for people with personality disorders take into account the childhood history of the person, difficulties they may have in engaging with therapy, as well as problems they may have around endings or moving on.
- Care plans, developed with the service user, should include short and long-term goals as well as a crisis plan, and should normally be shared with the GP.
- Contact with services should be medium or long-term, hopeful, collaborative and empowering.



"Putting something back
into the system that had
helped me,

gave me a sense
that what I'd been through
was not in vain."

6 Service user involvement

What does the term 'service user involvement' mean? Service user involvement can take many forms, but all types of involvement are focused on ensuring that the views of people who **use** services help to shape the way we **understand** mental health and the services provided, leading to real, sustainable changes and improvements in those services.

There are many different ways of doing this, but common examples include encouraging service users to be actively involved in their own care, or to have a say or an active role in the design, delivery and evaluation of mental health services. The principle which underpins this is that people with lived experience of mental health issues/using services have a valuable perspective; making a contribution in this way is beneficial both to that person and their development, and beneficial to the development of services.

Co-production is a term that is becoming increasingly popular. It refers to a broad range of involvement activities where staff and service users enter into a collaborative relationship, working together and recognising one another's different skills and experience as equally valuable. This approach draws on the understanding that both staff and service users need to be empowered to be able to work in partnership together.

What are the types of service user involvement?

In practice, service user involvement in mental health services in community settings can be applied across five main areas:

Service users involved in their own care: for example, someone's own view of their difficulties being taken into account in assessment, the service user having a say in their treatment and care plans, being listened to in care planning meetings. You might think about this as a shift from doing things to people, to doing them *with* people.

In service planning and evaluation: for example, giving feedback on the service; taking part in focus groups; service users working as researchers to evaluate the service, membership in clinical governance and service development structures.

Recruitment and training of staff: service users sitting on staff interview panels with an equal say to other members; facilitating training; running staff inductions.

In service delivery: This might be through direct service delivery such as service users facilitating groups, working alongside staff to co-facilitate assessments, providing service inductions. Another approach is to involve service users in reflective forums for staff such as case management meetings, case formulations, complex case forums, group supervision.

Approaches to involvement

As with any large, diverse group of people, there are widely varying views, experiences and ways of understanding personality disorder among service users. **There is no single service user perspective.**

To overcome this sometimes people might ask for a **service user 'representative'**, whose role is to represent others. If you choose a representative model it is important to think about who the individual needs to represent (i.e. identify their constituency) and how they will gather the views and ideas of those they represent (e.g. through a service user group meeting or via a service user network).

“How can I represent others’ views when I have no way to access other service users, or only become aware of the issues to be discussed the day before the meeting?”

Another approach to involvement is to involve those with specific experience and skills and recognize that this is valuable in itself. Sometimes people working to this model are known as **experts by experience**. Experts by Experience are valued in their own right and asked to bring their own perspective to the table rather than representing others.

There are also independent service user led organizations which work collaboratively with those providing services in service development, evaluation, training and so on.

In thinking about involvement it is important to ask yourself what you hope to gain, and to use this to inform what approach you take.

What is unique and different in respect to service user involvement and personality disorder?

As highlighted in other chapters, many service users with a diagnosis of personality disorder have complex histories of trauma, abuse, neglect or loss. These histories often go hand in hand with years of chronic invalidation, rejection and simply not having their experiences or opinions heard or respected. Some service users with personality disorder have also experienced turmoil or difficulties in their relationships with others, so their interactions with mental health practitioners can often be fraught and problematic. This has often led to individuals being described as ‘difficult to work with’, ‘attention seeking’, ‘manipulative’ or ‘untreatable’ and frequently excluded from services.

Due to these kind of experiences, many service users may mistrust authority and service providers. For some who do speak up, their feedback or opinions are often minimized or dismissed outright because of stigmatising or discriminatory views about personality disorder; this serves to perpetuate feelings of invalidation and mistrust on both sides.

“When I gave what I thought to be considered and thoughtful feedback about the service I was receiving, it was immediately dismissed because the common opinion amongst the service was that all that service users with personality disorder do, is complain... One member of staff even said to me; ‘well you would say that, that’s because you have personality disorder’, Another member of staff said ‘it’s part of your pathology’ as if my internal difficulties were the reason the service was poor and not because of the service or the trust’s failings.”

It is extremely common for people with personality difficulties to struggle with problems of identity; many people find it impossible to hold onto a sense of who they are. As people progress through treatment this can become more pronounced; as past coping strategies are left behind, people often ask ‘what’s left?’ ‘Who am I if I’m no longer ‘a self harmer’ or ‘an alcoholic’ or ‘the crazy one?’ Involvement activities can provide a space for people to begin to explore **new roles and ways of relating** to people. This uncertainty about identity is a core feature of the experience of personality disorder, so there is immense therapeutic potential in providing spaces where this can be experimented with.

One of the most misunderstood aspects of personality disorder is that individuals who attract the diagnosis may be bright, articulate and have extremely high functioning sides alongside the poorer functioning and the complex emotional difficulties associated with their diagnosis. These ‘opposites’ can pose a number of challenges for service users and practitioners alike. Sometimes there is surprise or shock at just how well someone can contribute:

“I was invited to sit on a clinical improvement group for my community mental health team, chaired by the senior medical consultant of the team. At the end of my first meeting, the consultant turned his head to me and said ‘I’m surprised, you made a very valuable contribution to the meeting’, what did he expect a service user to do, sit and dribble in a corner? That comment made me realise that the expectations of service users were low and involvement was a tick box exercise... they genuinely didn't expect a service user could make a valuable contribution. I then went on to think, if this was the view of the head consultant, what sort of example was he setting for the rest of the team? And no wonder the service was poor. I felt his back-handed compliment was humiliating and disrespectful and subsequently lost all hope in the service to help or understand me or others like me.”

Although the growth of authentic and meaningful service user involvement in the field of personality disorder has been problematic, there is nonetheless room for immense optimism when both the concepts of personality disorder and involvement are understood and worked with appropriately as Haigh et al (2007) describe:

“Many users of services may have a complex history of abuse, neglect or rejection and the opportunity to embark upon activities that shape and direct the services they receive promotes inclusion and therapeutic growth in itself. Many service users exceed expectations, not only in terms of their individual recovery, but in their subsequent contributions to services and their ability to sustain work and meaningful activity in the future. The social implications are phenomenal and cover numerous areas: pathways back to work or education become realistic; appropriate use of other NHS services provides substantial financial saving; problems with housing and social services can be resolved; offending behaviour reduced or stopped; and most importantly the quality of life for the user improves dramatically, with new-found social inclusion and a life felt to be worth living.”

What are the principles of good service user involvement?

1) SUPPORT

It's important not to make assumptions, but to have an open, honest conversation about what someone might need to enable them to participate. Ask yourself and those involved:

- What support might someone need? This might be emotional support, but may also be practical support.
- Who is the best person to provide emotional support, related to the involvement activity, if needed?

2) CLEAR EXPECTATIONS

Provide realistic expectations for involvement – both to professionals and service/ex-service users. It may be helpful to consider;

- Why do you want to involve service users?
- Why does the service user want to get involved?
- What does the role entail? For example what is the time commitment, responsibilities, details of the role? It is often helpful to write a role description to ensure that

everyone has a shared understanding of the role.

- What skills are needed? Most involvement activities require skills of some sort – if you can identify this at the beginning you can help people decide whether they are right for the role, or go through a recruitment process, to avoid difficulties later.
- What can be changed/influenced and what are the limits of the involvement? Be honest about the limits of service users' influence.

3) PAYMENT

It is widely accepted as good practice to pay people for their involvement (except in their own care). This demonstrates that the work of service users is valued and on a more equal footing with the views and opinions of staff.

A good starting point is the report produced by the Mental Health Research Network (see **Appendix 2**)

4) WHO TO INVOLVE?

Careful consideration needs to be given to the question of who to involve. It might be helpful to consider:

- What type of personal experience is important? Some involvement activities are directed at those who are

currently using a particular service; for others it might be helpful if someone has moved on or graduated from the service.

- Beware of 'cherry picking' individuals, and instead identify what experience people need to have to undertake the role.

5) DIVERSITY

In thinking about who to involve ensure you consider the diversity of the population you work with and try to ensure involvement activities reflect this. It might be helpful to ask yourself:

- Who uses our service? Who is eligible to, but does not access our service?
- Consider people from minority ethnic communities, those who identify as lesbian, gay or bisexual, gender, including those who identify as transgendered, religious groups and those with physical disabilities/sensory impairments.
- Often it is helpful to adapt involvement activities so they are more appealing to those who might not generally join in, for example, consider the location, linking in culturally appropriate creative workshops, collaborating with community groups.

6) ISSUES OF POWER

There is an inherent power imbalance between people who use services and staff that provide the service. Traditionally most professional trainings and services were based on a view of staff as holders of knowledge and expertise, and service users as ill, damaged, and therefore incapable. On a conscious level, many staff no longer believe this but services are usually framed with this model of ‘knowledgeable professional helper’ (staff) and ‘person to be fixed/helped’ (service user) at its core.

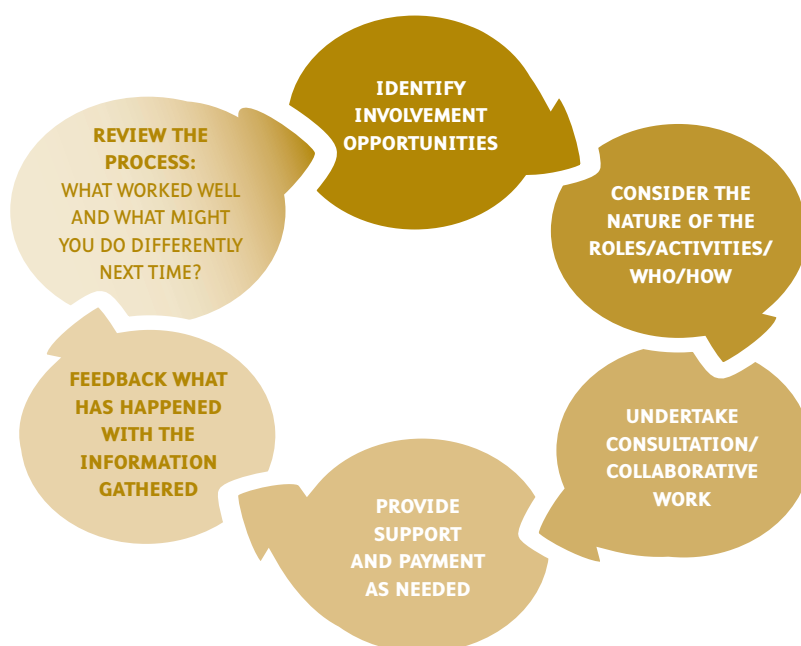
- Meaningful involvement requires everyone to reconsider and try to step outside these roles.
- Letting go of a position of ‘knowing’, which is so often a part of our professional identity, and inviting others to see our uncertainty, is often very unsettling and can be uncomfortable. This can also be the case for service users; for some, inhabiting a position of responsibility and authority will be a new experience which challenges assumptions they may hold about their own capabilities and identity.
- This does not mean devaluing the expertise and knowledge which staff have, but rather, recognising that service users have different forms of expertise and knowledge. The potential of involvement to deliver change and improve services arises from bringing together these two different types of knowledge and expertise.

- Power differences can also arise from lots of other factors such as age, gender, level of education and social class. These equally need to be attended to and carefully considered.
- Both staff and service users benefit from reflective space where these issues can be honestly explored.

7) FEEDBACK

The process of involvement does not end with the activity itself; feeding back what has happened as a result of service users’ input is crucial.

- We’ve all been in situations where we are asked our views and then hear nothing more – it’s frustrating and prompts the question, what was the point?
- Providing feedback helps to maintain involvement in future activity.



What are the challenges associated with service user involvement?

Some of the named challenges to involving service users in service design, development and evaluation include:

- **They're unreliable!** Stigma and discrimination can underpin the belief that service users are 'ill all the time' and therefore unreliable. Service users do have considerable coping skills, strengths and resources.
- **They're TOO well!** On the other hand, service users can be 'too well', 'too articulate' or 'too vocal'. Some workers are often looking for the 'typical patient', often someone who is passive and will not challenge the system or the practitioner viewpoint
- **We can't pay them!** Does your organisation have a policy in place for paying service users? If you cannot pay people, how will you reward service users for their input? There are other ways to give back – can you organise a meeting around a working lunch and provide food?

- **It takes too much time!** Consulting others, working collaboratively, these do all take time but try to think about the process as well as the end result – by involving people well you are working towards your therapeutic aims as well as service development.
- **It's always the same people!** Welcome the input of regulars while continuing to seek new people. Word of mouth is the best way to attract people – make people want to get involved.

What are the benefits associated with service user involvement?

Involving service users in the development and running of the mental health services they use has benefits for all: service users, staff, services and commissioners.

BENEFITS FOR SERVICES AND STAFF

Staff can find out more about what service users want and can develop responsive services. The relationship between staff and services

users will be strengthened if service users feel that their views and contribution are taken seriously. Involvement activities offer a chance to see people in a different role and to see their abilities and growth.

BENEFITS FOR SERVICE USERS

Service users can feel empowered by getting involved in this work, and it has been shown to strengthen self-confidence and self-esteem. Peer support from other service users can also contribute to recovery. The increase in confidence, as well as developing new skills, has led many service users into paid employment. Involvement offers an opportunity to explore new roles and identities beyond that of service user.

“Evidence shows that involving service users with a diagnosis of personality disorder can be therapeutic itself, by improving self-confidence and self-esteem.”

Learning points from **Chapter 6**

Service users with personality disorders have often had experiences of feeling mistreated or invalidated, both as they were growing up, and later if treated unhelpfully by services.

- Becoming involved in contributing to services can enable the person to use their past experiences in a constructive way, to contribute to the review, evaluation, delivery and planning of services.
- Service user involvement enables the service user to feel empowered, to try out new roles and to use their knowledge and skills, and may be a stepping stone to paid employment
- Services benefit from attending to service users' views and perspectives, which are often refreshing, challenging and different
- It is important that service user involvement is set up carefully, with thought about who to involve, establishing appropriate expectations, providing support when necessary, and payment or expenses if appropriate.

"My behaviour
exasperated my social worker
so much



she did what i always expected her to do -
she handed me over
to someone else,
and left."

7 Surviving or thriving at work: what helps staff?

All encounters with other people have the potential to leave us feeling fulfilled and engaged, or stirred up, unsettled, frustrated or depressed. Working with people with complex emotional needs or personality disorders is no different.

We all know that this work can be rewarding, engaging, often moving, sometimes funny, and ultimately very worthwhile. But personality difficulties shape how a person relates to others, and so the relationship between a worker and service user can be complicated. Because people with personality disorders have often had unhappy, difficult or traumatic experiences with those who were meant to care for them in childhood, they may be wary of people who try to help them in adulthood. This poses particular challenges for frontline staff who work with them.

On first impression, a service user who attracts a diagnosis of personality disorder may appear to reject help, or to be intent on harming him/herself or another person. In fact, the service user who appears to reject help may be communicating that in her/his experience, ‘help’ can be abusive and should be treated with suspicion. Rejecting help cannot be taken at face value. This makes the work demanding and stressful for staff.

To be skilled at this kind of work, a person needs to be emotionally affected by the work, but being affected by the work may sometimes mean that we are overwhelmed, upset, or do not function as well at work as we would like to. This aspect of working with people means that services need to be designed to provide thinking spaces or reflective forums, where staff can discuss feelings in relation to the task, roles and principles of the service.

Working with people in pain or distress is painful and distressing at times. It is not always easy to admit to the feelings we may have towards people we are meant to be trying to help.

Most frontline staff (if they are honest) will have encountered service users in relation to whom at times they felt:

- Frustrated.
- Hopeless.
- Confused.
- Anxious.
- Aware of uncomfortable parallels between the service user’s life and their own.
- Guilt that they are not offering enough.
- Angry and resentful that the service user seems ungrateful.
- Guilt – or relief – that their life is not so troubled as that of the service user.

Everyone needs time and space to recognise, and process what they are feeling in relation to their work, and in particular, in relation to service users who stir up strong feelings in the worker. This is rather like digesting a meal: we need time to chew things over, reflect on them, come to terms with them, and take in and learn from the important lessons. With help from others, we can also work out what are our own issues, and what might be an understandable reaction to the service user’s issues.

There are many ways of getting this support.

The work of trying to understand these kinds of feelings can be done in groups, such as reflective practice groups or group supervision, or through discussions with a supervisor or colleague.

Some professions, like counselling and psychotherapy, require trainees to have personal therapy so that the person has an opportunity to explore their own issues and their reaction to the work while training. Some workplaces offer access to a limited number of sessions of counselling every year to employees. This can be a very helpful way of 'digesting' the challenges of your role.

Talking to friends or partners outside work is not usually a good idea if what is stressing you is a particular client or service user, because of the need to respect the confidentiality of the service user. It is better to find someone within your workplace, who is bound by the same rules as confidentiality as you, a friend, colleague or manager, to discuss problems in relation to a particular service user.

Wellbeing and burnout

If we feel supported by the team, managers, and the organisation in which we work, this can be extremely rewarding work. However, staff who feel unsupported or confused about what is expected of them, or who feel that they are expected to do things for which they are not equipped, can experience **burnout**.

Ask yourself the following questions to see whether you might be suffering from burnout in relation to your work:

- 1) Do I feel run down, drained and exhausted, without any obvious physical explanation like being unwell?
- 2) Do I get irritated with my colleagues and team for no good reason?
- 3) Am I sometimes less sympathetic with service users than I should be?
- 4) Do I talk about clients in a cynical or harsh way?
- 5) Am I feeling that there is more work to do than I can possibly do?

'**Well-being**' is feeling energetic and committed to what we are doing, and feeling that we get satisfaction from our work. When we experience well-being, we usually have the energy to engage in a helpful way with service users, colleagues, and the job that needs to be done.

'**Burnout**', on the other hand, occurs when there is an expectation of someone being involved in difficult work that is not matched by them having a manageable workload or by them getting appropriate support and supervision. Organisations which allow staff to burn out are damaging not just for the staff member, but will ultimately not be helpful for the service user.

If we as individuals, and the teams and organisations that we work in, do not recognise how stressful the work is sometimes, we may develop a particular set of defences to try and protect ourselves from this stress. These defences are understandable, and may assist us in the short term to feel better, but they do not create a helpful and constructive work culture that is sensitive to the needs of service users.

Common defences against the distress stirred up by getting involved in the work

- Cutting off from service users and treating them in a distant, superior or critical way.
- Retreating to the relative calm of paperwork or unnecessary staff meetings.
- Getting promoted to management roles where there is less contact with service users.
- Passing cases on to someone else when you feel hopeless about being able to help.
- Becoming cynical about the work or resorting to 'sick' humour with colleagues.
- Becoming very business-like and efficient but at the risk of being insensitive.

When these defences get built into the culture of the organisation, they can lead to rigid, distancing and inhuman practices. There have been some very high-profile examples of things going badly wrong in health service organizations and care homes. But the factors that led to these and other profound human service failures exist in embryo in every service. Every service needs ways of supporting its staff to cope with being exposed to human pain and distress, and without such safeguards, unhelpful practices may develop.

STAFF TRAINING

One particular programme, the **Personality Disorder Knowledge and Understanding Framework (PDKUF)** was commissioned by the Department of Health and Ministry of Justice specifically to help staff working with people with personality disorders. It is worth finding out whether there are PD KUF courses available to staff in your area. Individuals may access the PD KUF training individually, or book a course for their whole team. Teams that train together are more likely to develop helpful shared working practices.

What do you need in order to do this work?

Work in this area is demanding, and the business of providing services is complicated. Front-line staff and their managers need to be working in teams which are functioning well enough to:

- Recognise (notice).
- Take in (digest).
- Make sense of (think about).
- Decide how to respond (intervention decision).

Teams need to do this in response to a variety of challenging situations on a daily, sometimes hourly, basis. These are ordinary human capacities but they can be affected by the strains of doing the work and by problems within the organisation. Organisations can design clear structures but if the team is not attended to with the same degree of care, it will be difficult to get the work done well.

CHECK OUT YOUR TEAM – HOW GOOD IS YOUR TEAM AT:

Recognising

Assessing the situation thoroughly; listening to what is said, what is communicated through action, and the hidden messages about how someone feels that may not be put into words; attending to detail; seeing the bigger picture (not just the service user's difficulties but also their strengths as well as their family, friends, carers, dependent children).

Taking in and making sense

Discussing, reflecting, trying to understand complex and sometimes confusing or contradictory information, considering alternative courses of action.

Deciding how to respond

Being clear among yourselves and with the service user and other involved agencies about a recommended course of action; recording and communicating the plan taking into account confidentiality and the service user's wishes, as well as who needs to know.

Developing your capacity to work with people with personality disorders

The qualities a worker needs, in order to work effectively in human services, are rarely routinely developed in professional training; for example, trainings for many roles and professions are aimed at 'what to do', but not 'how to be'. Yet it is this 'how to be' that is so important to the service user, and ultimately to the work which the worker is able to carry out. Of course, the training in 'what to do', is important but how that is used will depend on the unique personality of the worker. Working with people with personality disorder does not suit everyone. Some people feel more at home working with those who have different types of problems.

Some of the qualities which are useful for someone working in the field of personality disorder:

- A strong enough sense of your own self.
- Sufficient interest in and curiosity about others.
- Ability to show compassion—empathy and kindness, without obligation.
- Appreciation of the complexity of human beings.
- Flexibility in relating to others.
- The capacity to bounce-back from difficulties.
- Clarity about boundaries and limits.
- The ability to be responsive without being reactive – taking personal comments seriously, without getting personal in response.
- Ability to learn from experience, and to bear making mistakes.
- Ability to be connected to someone but separate, so that you do not intrude on them, nor let them intrude inappropriately on you.

These qualities come and go in daily life: under conditions of stress or anxiety, people fall back on more inflexible ways of operating, and seek to push away discomfort and threats (and, sometimes, responsibility too) by looking for simple solutions. It is useful, therefore, to think in terms of people being in different **states of mind** – one like the state which allows for the qualities listed above, and a second state which is characterised by the more inflexible way of being, in response to stress or anxiety.

It is possible to think of the first state as being more or less ‘open’ to the complexities of life, and the second as being more or less ‘closed’ or inflexible, as a way of coping with, or dealing with, life.

Both states of mind have their place in work and in life – there are times when more openness, is needed to foster receptivity and mindfulness, and times when more of an inflexible state is required, so that decisions can be made and action can be taken. Most of the time, whether at work or elsewhere, we all move back and forth, or ‘oscillate’, between these states

These states of mind are part of what makes workers and service users similar to each other, but are also where difference arises: the worker needs to be able to move more flexibly, and to respond to the immediate situation appropriately, in order to be able to help the service user, who may be more likely to get stuck in a particular way of thinking.

A worker’s capacity to function as well as possible at work, will depend a great deal on the team and organisation in which they work, how this functions, and the support which this provides to each individual worker.

Working in teams

Working in teams (i.e. groups of three or more people focussed on the same task) is the best possible way to deliver services to people with complex psychological, social and behavioural difficulties. In a team we can share ideas, think together, support each other, share responsibility for difficult decisions, and make it more likely that somebody will be available who knows about a particular service user if they need urgent help.

All teams need to be clear about what they are doing, who is going to do what, and agree how to go about it. If these things aren’t clear, workers will feel confused and service users are likely to suffer. Because people with complex needs are often experiencing confusion themselves, or may be very sensitive to neglect or mistreatment, it becomes particularly important that teams are consistent and convey consistent messages to service users.

BEING CLEAR ABOUT THE TASK OF THE ORGANISATION

It benefits staff and the service user if services clearly describe their purpose, or task, and the ways they go about this task. It is also useful to describe what the task is NOT. In this way, the sense of limits, or boundaries, of the service can also be understood from the start. Services usually have an overall primary task, with different sub-tasks contributing to the main task.

“My keyworker at the Vocational Support Service had trained as a counsellor, and he behaved as if he was my counsellor, but I needed help to find and get onto a particular training course. I didn’t want to talk about things endlessly, I wanted to do something to make me feel better about myself. That’s what they told me they would do with me. I left the service, because I couldn’t explain to anyone that I didn’t think he was doing the job he was supposed to be doing.”

Service User

“In this new team, we are very clear about our primary task, but we are really struggling because different team members take different approaches to this task – some workers approach the young people as if they cannot help themselves, and try to do everything for them, get involved in all aspects of their lives. Others take the view that the young people have to be helped to take responsibility for their situation. This difference is very confusing for the people who use our service, and it’s leading to a lot of conflict in the team.”

Team Manager

ARE YOU CLEAR ABOUT THE TASK OF YOUR ORGANISATION OR SERVICE? WOULD YOU BE ABLE TO COMPLETE THE FOLLOWING SENTENCES?

- My service exists in order to ...
- There are services we don’t offer, like ...
- There are people whose problems fall outside our remit. This would include ...
- A mistake that people commonly make is to think we do ...

BUILDING A SHARED PICTURE

Service users benefit if services have a clear and shared **approach**, an idea about how personality disorder develops, or how the personality of a human being becomes organised in ways that seem to be different from what is expected by the community they live in. In other words it helps if services have a ‘**model of the human mind**’.

There are a range of useful models of the development of personality disorder (see **Chapter 3 How does personality disorder develop?**). It will be important that the way the service thinks about personality disorder makes sense to the service user. While it helps to have a shared, coherent view of personality disorder, it can be unhelpful if this becomes fixed or rigid. If you are working with a model in your service which seems fixed, like a kind of ‘bible’, you probably need to think about why such certainty is necessary. Sometimes it is hoped that sticking rigidly to one point of view will give workers a sense of safety and security, but often it makes a service less safe, as it cannot respond flexibly to different individuals, situations or needs.

ORGANISATIONAL VALUES AND CULTURES

It also benefits the service user if the shared model or approach is explicitly linked to an ethos, or **set of values**, which describes why the service exists. An example of a set of values can be found in relation to the work of developing Enabling Environments (see *Enabling Environments* in *Chapter 5 What help might be available?*). In the absence of a clear value-base, hidden or tacit assumptions can hold more power; the risk is that these tacit assumptions can be destructive or discriminatory.

An example of a **tacit assumption** would be the unspoken idea that anyone who has had one unsuccessful attempt at treatment is bound to fail if offered a different form of treatment. If a service has an explicit policy that everyone's needs will be assessed irrespective of their previous engagement with services, then everyone knows where they stand. Without such a policy there is a risk that someone who has had a negative experience with a previous service might be seen as 'difficult' and workers might avoid offering them help.

ROLES AND RESPONSIBILITIES

In addition to clarity about the task and values of the service, it helps if there is equal clarity about **people's roles and responsibilities**.

Within your organisation do you know who to turn to for advice or authority:

- If you need to go home early because you are unwell.
- If you think a particular service user needs additional help from the normal service that you offer.
- If you think that someone is now ready to leave your service.
- If you discover an emergency situation at 4pm on a Friday afternoon.
- If you think one of your colleagues is over-involved with a client.

Even though it may take some time to establish clarity and consistency of these features, taken together they can begin to provide a **reliable environment for service users**, and a **good working environment for staff**.

These features of services offer a foundation for making decisions about work – such as what to do, when, how and where.

SUPPORT AND REFLECTION

Teams need **a place and a time to think together about the work**. This enables members of a team to develop shared agreements about their task and values, and a shared model of the work. It also enables staff members to share with each other the challenging, difficult aspects of the work, as well as their successes. Shared decision-making about risk assessment and management reduces the burden on the individual. It also makes it more likely that decisions will be made in the long term interests of the service user, rather than to reduce the anxiety of a team member. **A place and time to think is not a luxury, but a necessary part of the work**. Each service has to develop its own versions of thinking spaces. Some examples of thinking spaces include: mindfulness groups; reflective practice groups; work discussion groups; supervision groups; case discussion forums.

Learning points from **Chapter 7**

Some people do not like working with people with personality disorders, and may not be suited to this work. There are staff members who feel more comfortable working with service users who are more obviously 'ill'.

- There are also many of us who like working with people with personality disorders, who we can see are similar to ourselves, except that people with personality problems have got particularly caught up in unhelpful patterns of thinking, feeling and behaving, often in response to trauma or difficulties in childhood.
- Whatever the primary task of your organisation, and your role and responsibilities, it is likely that it is how you relate to people using your service, which will have a big impact on whether they benefit.
- Being open to observing, engaging with, and thinking about the people you work with, will at times leave you exposed to feeling troubled, upset, anxious, confused, and frustrated.
- To do this work, we need the support of teams, and clarity about what we are doing and how we are going to do it. Space to think, reflect, discuss, and get ideas and support, are essential to being able to do this work well, and being able to maintain wellbeing at work.

Appendix 1: Specific psychological therapies which may be available for people with personality disorders

The availability of different therapies varies across localities, but these therapies are all in use in different parts of the UK. No one area will have all of these therapies available, but one or more of the following may be offered in your area through mental health services, psychological therapies services, 'IAPT for PD' services, specialist personality disorder services, or through voluntary or other agencies:

A) DIALECTICAL BEHAVIOURAL THERAPY (DBT)

DBT is a highly structured treatment, developed to treat particularly the suicidal and self harming behaviour that can be a feature of Borderline Personality Disorder. It consists of weekly individual therapy, weekly group skills training, and out of hours telephone contact to support the service user in responding to emotional crises. In the first year or so of treatment the aim is to help the service user to stabilise impulsive and life-threatening behaviours by replacing them with emotion regulation and distress tolerance skills. There is also an emphasis on developing some psychological distance from difficult thoughts and emotions by the practice of mindfulness, or learning to pay attention to the experience of the present moment without judgement.

B) MENTALIZATION-BASED THERAPY (MBT)

MBT is a relatively new approach which is gaining in popularity. The standard MBT approach is a combination of individual and group therapy similar to the format of DBT. In some cases, it can also be offered as a group or an individual therapy. The capacity to 'mentalize' is the capacity to think about our own and others minds, in terms of mental states, thought, feelings and intentions. We learn how to mentalize by having other people, originally our caregivers in childhood, think about us and what is in our minds. Some experiences, particularly trauma, can disrupt our capacity to mentalize. Some people with personality disorders can mentalize quite well when they are feeling settled and stable, but if they become attached to

people and feel very stirred up, their ability to mentalize breaks down and they make inaccurate assumptions about others. In MBT the therapist adopts a non-judgemental, curious stance, and jointly with the client tries to understand the client's mental states, and so aims to strengthen the client's capacity to mentalize, even when they are stressed or upset.

C) COGNITIVE ANALYTIC THERAPY (CAT)

CAT is usually offered as a time-limited one-to-one therapy, with a course of 16 or 24 sessions. In the first 4 or 5 sessions the therapist will work with the individual to arrive at an agreed formulation of the person's problems, and will think of these in terms of repeating patterns in relationships, and associated coping strategies. Usually in CAT this formulation is both written down in the form of a letter from the therapist to the patient, and is drawn as a map showing how the person shifts from one state of mind to another. Once the therapist and client have agreed on the key issues which the person wants to address, these become the 'target problems' to think about and to try and change during the course of therapy. CAT emphasises that the relationship between the

therapist and client is a collaborative one, working together to understand how the client has come to develop their particular relationship patterns and coping strategies, and what would enable them to change.

D) TRANSFERENCE FOCUSED PSYCHOTHERAPY (TFP)

TFP is one type of psychodynamically-based therapy that has been found to help people with BPD. TFP is a one-to-one therapy that specifically focuses on the split in people with BPD between, on the one hand, their wish for idealised, perfect care from another person, and their experience, which is often of very disappointing, neglectful or abusive treatment. TFP makes a point of recognising and addressing the aggression and rage which may be felt very acutely by people with BPD, and the ways in which this may be a response to disappointment in relationships.

E) INTERPERSONAL GROUP PSYCHOTHERAPY (IGP FOR BPD)

There are a range of approaches to group therapy for people who might be diagnosed with a personality disorder. IGP, like CAT, aims to identify and understand

repeated patterns in the individual's relationship with others which are unhelpful. In IGP, the exchanges between members of the therapy group, and between the individual and the therapist, are seen to be an important source of information about the key themes which preoccupy that individual. There is a focus on the conflict between the person's wishes (often for comfort and care) and their expectations of others (often that they will be rejected or abused). The therapy explores where these wishes and expectations come from in the person's childhood history.

F) COGNITIVE THERAPY FOR PERSONALITY DISORDERS (CBTPD)

CBTPD is developed for the treatment of borderline and antisocial personality disorders. It is an effective short therapy for self-harming and suicidal people with borderline personality disorders and for men with antisocial personality disorder who are violent and living in the community. CBTPD is delivered individually in 30 sessions over one year. Therapy is based on a written formulation, agreed between therapist and service user, focussing on core beliefs about self and others and

problematic behavioural patterns. It is assumed that these core beliefs and problematic behaviours developed as a result of often distressing and traumatic childhood experiences, usually with care givers. After the initial five or so sessions to develop the formulation, the client and therapist work collaboratively to develop new more adaptive ways of thinking about self and others and more effective ways of coping.

G) SCHEMA THERAPY (ST)

ST is primarily aimed at treating those who have entrenched difficulties, associated with a diagnosis of personality disorder, in their sense of their own identity, and in relating to others. The approach assumes that personality difficulties develop from unmet core emotional needs in childhood, leading to the development of unhelpful emotional and cognitive patterns called 'Early Maladaptive Schemas' (EMS). Problematic behaviours are thought to be driven by underlying schemas. According to the model, schemas have different levels of severity and pervasiveness. The more entrenched the schema, the greater number of situations that activate it, the more intense the negative emotions

and the longer it lasts. It is assumed that everyone can relate to at least some of the schemas described in the model, although these may be more rigid and extreme in service users who seek treatment. Cognitive and behavioural techniques are core aspects of the intervention, but the model gives equal weight to emotion-focused work, experiential techniques and the therapeutic relationship. ST is a normally a long-term intervention (2-3 years); even with people with less severe personality disorders, fewer than 20 sessions is rarely enough. Therapy involves a gradual weakening of the dysfunctional parts of the personality structure through the strengthening of the healthy, adult part of the person.

H) INTENSIVE THERAPEUTIC PROGRAMMES

Most psychological therapies are provided on an out-patient basis, with appointments once or twice weekly as in DBT and in MBT. Many people can benefit from these approaches, but a few people find they struggle in the gap between appointments, and need more intensive help.

Some localities have day hospital or day programmes, where people attend up to 5 days per week, usually for a programme of different therapeutic groups and activities such as art and music therapy.

I) THERAPEUTIC COMMUNITIES

TCs were started during World War II, as a way of treating veterans who were psychologically traumatised by war. Therapeutic communities can be residential, or sometimes run as a day programme over a number of days a week. They operate a programme of different therapeutic groups and activities. TCs challenge the rigid split which sometimes exists between 'professionals' and 'patients' and aim to work as a community in which every member is seen to have a valuable contribution to make to other people's development. Service users usually have a say in day-to-day decision making about how the community is run, and staff and service users will together make decisions about handling crises, or when someone is ready to leave.

The aim is that individuals will be helped with their own problems, but will also be empowered by discovering their capacity to take responsibility and to help others.

J) ARTS THERAPIES

There are different forms of arts therapy, most common are art therapy, music therapy, drama therapy and dance movement therapy. They usually take place in a group and service users do not need any prior experience, skills, or abilities in the particular art. They are all based on the principle of creating a safe and trusting environment where an individual can access and express strong emotions. They enable people to express emotions non-verbally that they might not otherwise feel able to express.

Appendix 2: References and resources

REFERENCES:

Moran, P., Leese, M., Lee, T., Walters, P., and Thornicroft, G. (2003) **Standardised assessment of personality – Abbreviated Scale (SAPAS): preliminary validation of a brief screen for personality disorder.** *British Journal of Psychiatry*, 183, 228-232

Turner, K., Lovell, K. and Brooker, A. (2011) **'...And they all lived happily ever after': 'Recovery' or discovery of the self in personality disorder?** *Psychodynamic Practice: Individuals, Groups and organisations*, 17 (3), 341-346

USEFUL RESOURCES:

For immediate help:

Call **111** if someone needs medical help fast but it's not a 999 emergency. A team of advisors, supported by nurses and paramedics, will ask questions to assess the situation and give healthcare advice or will direct the person to a suitable local service.

With a life-threatening emergency, call **999** or go to the nearest **A&E**.

The person's **GP** may be able to offer support themselves, or refer the person to specialist mental health services. If the GP surgery is closed they will have an out of hours' service that can be contacted instead.

The Samaritans are there to listen 24 hours a day. Call on 08457 90 90 90. The Samaritans' website gives information about call charges www.samaritans.org

Saneline offers emotional support out of office hours and is open every day 6pm to 11pm on 0845 767 8000.

Most areas have a **mental health crisis team** available 24 hours a day; their contact details should be available via the local council or social services, or they can be contacted via A&E.

GENERAL SUPPORT:

Local mental health charities – most local mental health charities have information about support available in the area. Many also run services such as day centres and social groups themselves.

To find out about local mental health charities check the local phone book, contact **MIND** www.mind.org.uk to see if they have an organisation in your area, ask at a local GP surgery or local library.

Emergence is a specialist service-user-led organisation supporting all people affected by personality disorder through support, advice and education. The Emergence network as a whole has access to a large amount of information about personality disorder, different treatments and services. If you cannot find the information you need on their website please do contact them at admin@emergenceplus.org.uk and they will try their best to help.

GOVERNMENT POLICY DOCUMENTS AND GUIDANCE:

National personality disorder website: www.personalitydisorder.org.uk

Personality Disorder: No longer a diagnosis of exclusion. NIHME, 2003. Available online: www.personalitydisorder.org.uk/assets/resources/56.pdf

Recognising Complexity: Commissioning Guidance for Personality Disorder Services (2009) Available online at www.pn.counselling.co.uk/recognising_complexity_june_09.pdf or www.personalitydisorder.org.uk/recognising-complexity-commissioning-guidance-for-personality-disorder-services/

Breaking the Cycle of Rejection – The Personality Disorder Capabilities Framework. NIMHE 2003. www.spn.org.uk/fileadmin/spn/user/*pdf/Papers/personalitydisorders.pdf

NICE Guideline on Borderline Personality Disorder
www.nice.org.uk/CG78

NICE Guideline on Antisocial Personality Disorder
www.guidance.nice.org.uk/CG77

NICE Guidance on Self-harm
www.nice.org.uk/CG16

Department of Health and Ministry of Justice approved training and courses in personality disorder:
www.personalitydisorderkuf.org.uk/

Review of the pilot projects in personality disorder services (2011)
www.personalitydisorder.org.uk/news/wp-content/uploads/Innovation-in-Action.pdf

Learning the lessons. Evaluating services for people diagnosed with personality disorder. NIHR (2008)
www.nets.nihr.ac.uk/__data/assets/pdf_file/0020/81380/RS-08-1404-083.pdf

Personal accounts of living with and overcoming personality disorder:
Rachel Reiland (2004). Get Me Out of Here: My Recovery from Borderline Personality Disorder. Hazelden, USA.

Kiera Van Gelder (2010) The Buddha and the Borderline: My Recovery from Borderline Personality Disorder Through Dialectical Behaviour Therapy, Buddha and Online Dating. Oakland CA: New Harbinger Pubs Inc

General and specialist reading:
Ministry of Justice (2011) Working with Personality Disordered Offenders. A practitioner's guide. Ministry of Justice Offender Management Service, Crown Copyright. Available online at www.justice.gov.uk

Anthony Bateman and Roy Krawitz (2013) Borderline personality Disorder: An Evidence-Based Guide for Generalist Mental Health Professionals. Oxford: Oxford University Press. (Contains information on Structured Clinical Management).

David Healy (5th edition, 2009) Psychiatric Drugs Explained. Churchill Livingstone, Elsevier Ltd

Jeffrey Young, Janet Klosko and Marjorie Weishaar (2003) Schema Therapy: A Practitioner's Guide. NY: Guildford Press

Michaela A. Swales and Heidi L. Heard (2009) Dialectical Behaviour Therapy: Distinctive Features. Routledge.

Heather Castillo (2003) Personality Disorder: Temperament or Trauma? London: Jessica Kingsley Publishers.

K Turner, S Gillard, M Neffgen (2011) Understanding Personality Disorders and Recovery. Available via Emergence: admin@emergenceplus.org.uk

SELF HARM:

National Self Harm network:
www.nshn.co.uk

Lifesigns – a User-Led organisation working around self injury providing guidance and opportunities to network with others: www.lifesigns.org.uk

For health professionals wanting to know about the toxicity of ingested drugs, **The National Poisons Information Service** can be contacted on 0844 892 011 for advice on complex cases or multiple ingestions. This service is for health professionals only; members of the public should call 111 or 999 as appropriate.

SERVICE USER INVOLVEMENT:

MHRN Service Users & Carers Payments Policy Benefits Conditions and Systems around Paid and Voluntary Involvement Version 3.0 August 2013 is available online www.mhrn.info/pages/mhrn-model-payment-policies-for-service-users-and-carers-.html

NSUN National Service User Network: www.nsun.org.uk

WEBSITES:

A directory of phonelines is available via the Helplines Partnership: <http://search.helplines.org>

Mindfulness meditation – web based supported meditation programme www.getsomeheadspace.com

CBT based self help resources: www.getselfhelp.co.uk/selfhelp.htm

ACTIVITIES PEOPLE WITH LIVED EXPERIENCE OF PERSONALITY DISORDER RECOMMEND:

Volunteering – For opportunities and to find local volunteer centres go to www.do-it.org.uk

Meetup – to find a group of like-minded people or those with similar interests. www.meetup.com

dragoncafe.co.uk – a physical café in London, which also offers a range of online resources for anyone affected by mental health issues.

The Ramblers – Find local walking groups at www.ramblers.org.uk



This publication is available online at www.emergenceplus.org.uk

July 2014