

*“Shining lights in dark corners
of people’s lives”*

The Consensus Statement for People with
Complex Mental Health Difficulties who
are diagnosed with a Personality Disorder

Centre for
Mental Health



Royal College
of Nursing



Royal College of
General Practitioners



The British
Psychological Society



Anna Freud
National Centre for
Children and Families



Consensus statement: People with complex mental health difficulties who are diagnosed with a Personality Disorder

Shining lights in dark corners of people's lives

"I have come across countless individuals and families, in my work as a minister and as an MP, who have been let down by mental health services. There has been some encouraging progress over the last few years, with mental health gradually brought out of the shadows and more people accessing treatment. But I am still horrified at the scandalous neglect and exclusion of those given a diagnosis of 'personality disorder' .

"The disadvantages they face – not just in the NHS, but in wider society – are clear. Lower life expectancy, inadequate access to treatment, barriers to employment, and a lack of awareness in society. This is especially unjust when we know what approaches are effective in supporting people to live more fulfilling lives.



"This consensus statement is a call to action to stop the appalling treatment which people given a diagnosis of Personality Disorder too often experience. It is intolerable that the services we offer do not meet the needs of this group of people, when small changes could make such a difference. This report offers some important suggestions which offer hope to these people. It is vital that government and the NHS grasps the urgency of this."

Rt Hon Norman Lamb MP

"It has long been my experience, that people like me given a diagnosis of 'personality disorder' often do not get the help that we need. We are often diagnosed and then there are no services set up to help, we are misunderstood, stigmatised and our lives are shortened by 19 years in relation to the average population.



The worst statistic is that many of us (1 in 10) die by suicide and it seems that people just don't care. People are affected from all walks of life but poverty and childhood trauma is often a big factor. Some end up in the prison or the forensic system which I find really saddening.

There are pockets of excellent practice around the country - we just need to galvanise and spread them throughout the UK. The aim of this report is to highlight the many issues surrounding 'personality disorder' to raise awareness and to hopefully bring some help for people such as health checks which are given to people with psychosis, the right treatment at the right time, including helping people when they are young so the onward economic and personal cost of a life lived in services can be halted.

People given a diagnosis of 'personality disorder' have been left in the wilderness for too long and it's about time the system as a whole, such as health, social care, housing, third sector and community initiatives come together to bring help and hope."

*Sue Sibbald, Peer Specialist.
Co Chair, Personality Disorder Consensus Group*

Who are we talking about?

Our personality is the collection of characteristics that make us distinctive as people. Most people develop enough awareness of their personality characteristics and, most of the time, can keep them in good enough balance that they can do what they need to do in life, be reasonably happy most of the time and have stable relationships which satisfy them and others.

Unfortunately, some people experience persistent distress in their lives and it is these experiences which contribute to them being described as having a personality disorder. Broadly this is described in diagnostic manuals as follows:-

- An enduring pattern of emotional and cognitive difficulties which affect the way in which the person relates to others or understands themselves.
- This pattern of behaviour is pervasive and occurs across a broad range of social and personal situations
- Is a long standing difficulty which always appears in childhood or adolescence and continues into later life
- May lead to significant problems in occupational and social performance
- Is not attributable to another mental disorder, substance abuse or head trauma.^{1, 2}

This diagnostic label should be helpful because it can act as a gateway for individuals to access the care they need. Unfortunately all too often it can be used as a reason to reject individuals from services. Most of us would rather not use the term at all. In writing this document, it has been hardest of all for us to get consensus on what words we should use to talk about the problems and difficulties people with this diagnostic label experience. We would like to abandon the term 'personality disorder' entirely. The label is controversial for good reasons: it is misleading, stigmatizing^{3,4,5} and masks the nature of the problem it is supposed to address, adding to the challenges which people experience. However, it has its advocates, not least among those for whom it has been the only passport to effective help. Currently, the label is used to allocate services and resources within the health and care system, so until an agreed alternative emerges we continue to advocate for an alternative way of defining this group of people.

The label of Personality Disorder is controversial and needs to change

When we talk about people whose needs this statement is concerned with, we mean that they have been given a *diagnosis* of personality disorder and never that they have *become* that disorder. Instead we need to understand a person in the context of:

- Individual experience – including early and persistent trauma, sexual abuse and other adversity^{6,7,8}
- Social and environmental factors – poverty, deprivation, migration etc.
- Diverse (protected) characteristics such as race, gender, sexuality affecting social inclusion/exclusion
- Their attachment and relationship history
- Physical variations which may predispose to regulating emotions or ‘reading’ emotions in others

All these factors interact with individual temperament and capacity to respond to stress. Together they can lead to the individual feeling frequently overwhelmed with unbearable feelings and find it very difficult to navigate the daily challenges of life.

People given the label of Personality Disorder are likely to have experienced past trauma.

How many people are we talking about?

About 1 in 16 worldwide have at some point been given a diagnosis of personality disorder⁹ and it is a diagnosis which is particularly common among patients attending general and psychiatric hospitals.¹⁰ Many are regular attenders in general practice. In the prison population, it is estimated that between 60 and 70% have met the diagnostic criteria of a personality disorder¹¹



They often find themselves living a precarious and isolated existence and over time, they are much more vulnerable to developing other health problems, such as anxiety and depression, as well as problems with their use of alcohol and drugs.¹² They are also more likely to have physical health problems such as cardiovascular disease¹³ and obesity¹⁴. Collectively, these problems exact a very heavy toll: compared to people who have not been given a diagnosis of personality disorder, men and women with this label live considerably shortened lives (18 years shorter for men and 19 years shorter for women)¹⁵. The shockingly elevated death rate appears to be due to those given this diagnostic label having a raised risk of ‘unnatural deaths’ (suicide, homicide and accidents) as well as ‘natural’ causes of death (such as infections, or cardiovascular disease)¹⁶. The NHS has not adequately met the complex needs of people given a diagnostic label of personality disorder¹⁷. For example, compared to service users with psychosis, people with a diagnosis of personality disorder do not receive parity of physical health care¹⁸.



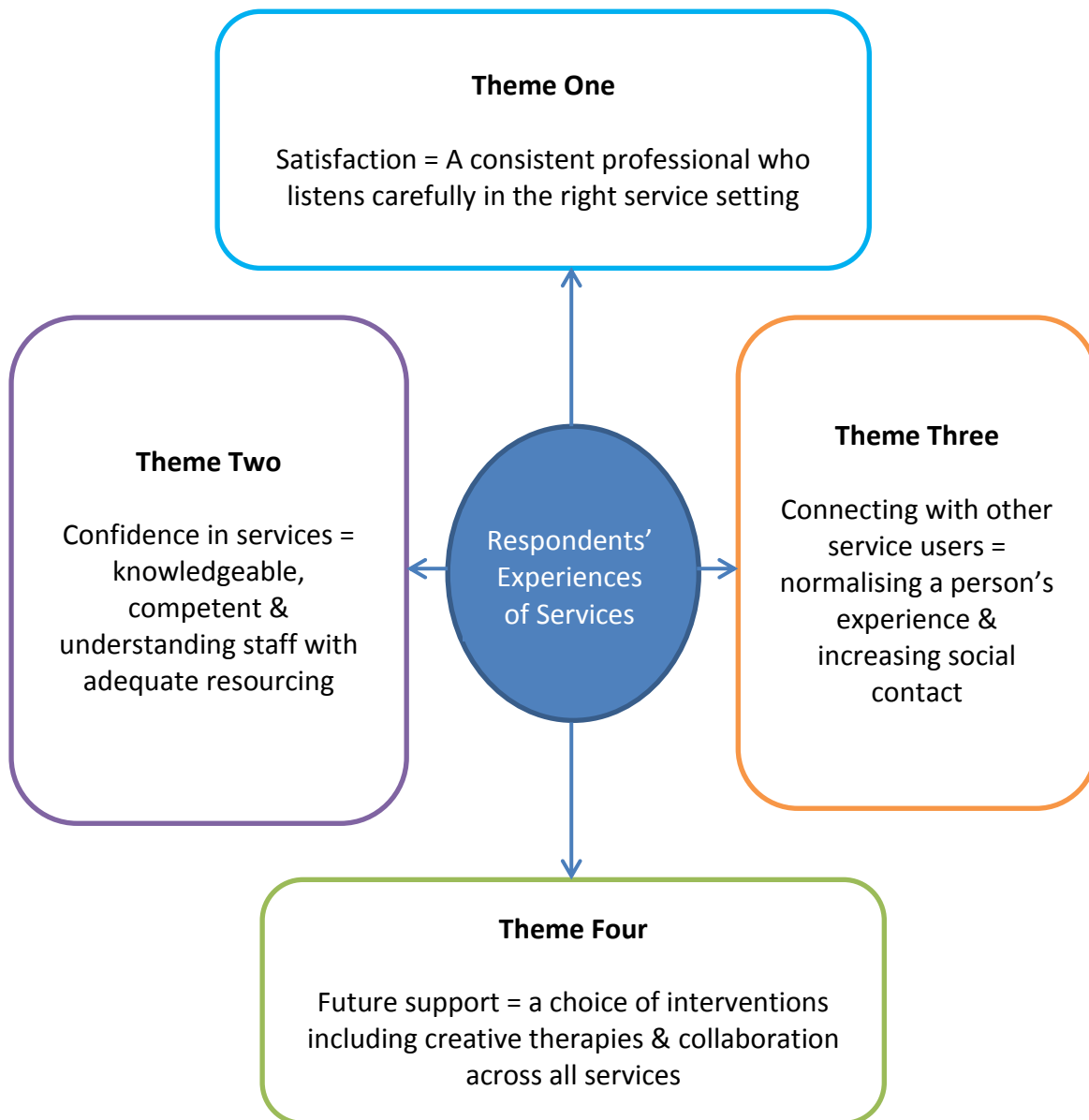
Men diagnosed as having a personality disorder die 18 years earlier than other men.

Women with the same diagnosis die 19 years earlier.



What do People with Personality Difficulties say themselves?

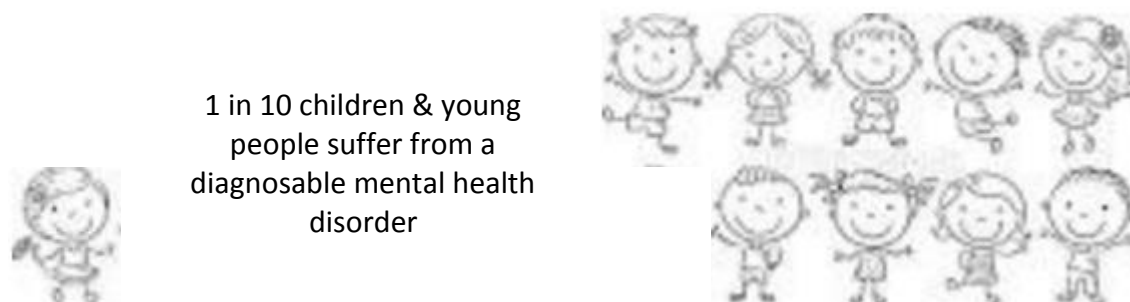
A recent survey publicised on social media and The National Survivor Network (NSUN) newsletter on behalf of the consensus group investigated what people found helpful and unhelpful within service settings. 281 respondents took part in the survey and analysis of their responses revealed four main themes which give pointers towards how services can be improved. Detailed results of the survey are described in Appendix A.



Whilst this can only describe a snapshot in time of a small group of people, it is likely that the comments made here do represent a wider view. This is because the comments made are consistent with the findings in much of the literature today and are echoed in policy documents and NICE guidelines.^{19, 20, 21} The views expressed here are not dissimilar to those consistently expressed by most people with experience of health and social care services where, for some reason or other, they have not fitted into the `box` of standard care that the system provides.

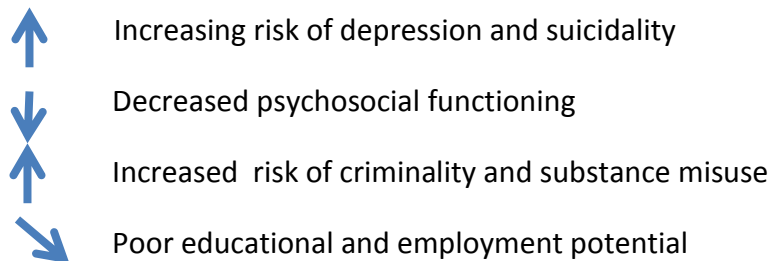
Stopping Difficulties Early On: *Let`s help as early as we can*

Today, increasing numbers of young people are demonstrating signs of distress. Studies reveal that less than half of adults experiencing mental health difficulties in childhood were offered appropriate interventions at the time.^{22,23} Current estimates suggest that 1-5% of adolescents in the UK could meet the diagnostic criteria for borderline personality disorder (BPD).



There is now evidence of a causal and proportionate relationship between Adverse Childhood Experiences (ACEs) (such as parental loss, exposure to domestic violence, physical, emotional or sexual abuse) and poor physical health, mental health and social problems in adult life.²⁴ Work in Philadelphia, USA highlighted that 45% of children experience 4 or more ACE`s and when they were identified in schools, suitable interventions were offered early on to stop difficulties developing later.²⁵ In a recent survey of adverse childhood experiences in England, 47% of the population reported experiencing at least one experience and 9% disclosed 4 or more.²⁶ (see appendix B)

Failing to recognise and address early warning signs in children and adolescents not only enable personality difficulties to perpetuate causing significant distress to the young person in the present, it also has considerable impact on long-term personal and societal outcomes. These young people can face:-



The critical importance of childhood and adolescence in setting the course for a healthy adult life make it essential that early signs are recognised and effectively addressed.

The good news is that if we ask people routinely about adverse childhood experiences as part of an assessment or care review process, people tell us about their childhood experiences and then start to make sense of their current difficulties in the context of their childhood adversity^{27, 28}. A history of trauma is so common that we have placed special emphasis on it, but it is important to recognise that some people may have similar difficulties without this.

Current thinking suggests that when devising a specific early intervention programme, it is vital to recognise that need for treatment may not be dependent on diagnosis. In other words, better outcomes may result if we stop waiting for people to get bad enough to receive a diagnosis, before we offer them any help.

Early intervention is essential: Asking the right questions early on helps to identify people's difficulties early on so that appropriate interventions can commence and stop things getting worse

Early Intervention Programmes for younger people should follow a clinical staging model, i.e. a model which provides a level of intervention appropriate to the distress at the time. In this model, at risk individuals who are showing signs of distress should receive generic trauma informed psychosocial interventions, such as mental health literacy, psychoeducation and supportive counselling. However, if two or more clinical indicators are observed, specific evidence-based programmes such as Helping Young People Early (HYPE) must be prioritised. If severity increases, case management, family psychoeducation, and more intensive psychosocial interventions such as Dialectical Behavioural Therapy (DBT) or Mentalization Based Treatment (MBT) may need to be added to the intervention.^{29,30,31}

What happens to people in later life?: Let`s help people through all stages of their lives

In comparison to younger age groups much less has been written about older people who are less likely to receive a diagnosis of personality disorder, but may still show signs of persistent distress which could be interpreted in this way. Anecdotally we know that the multiple losses which occur later in life may stimulate difficulties which may not have been seen previously. When people that they have been close to are no longer there to help them manage their lives, underlying problems in coping can start. Often their difficulties emerge in different ways but can be demonstrated as avoidance or anxiety which debilitates them.

A combination of dementia and difficulties associated with a diagnosis of personality disorder may be particularly challenging and may not be understood within current assessment services. Particular attention needs to be paid to older people to ensure that their needs are not forgotten and are properly understood and further research needs to be undertaken to understand this group of people better.³⁰

What are the challenges that face us and how can services respond?:

Let`s be clear about what we are doing now and what we need to do

In a recent survey, 84% of mental health trusts in England said they had a dedicated service for people with a diagnosis of personality disorder. However, only 55% of the same trusts had equal access to these services across their catchment area.³²

The literature about care and support for people with a diagnosis of personality disorder is broad and varied. While that can seem confusing, it is a tremendous advantage. It may be that each service setting will be restricted in the range or what it can offer, so we need to get better at collaboration: sharing and enabling people to move between centres of expertise to get the best fit for their needs. We do not need to focus on a single model: what is important is that there is wide availability of treatments which the evidence says is effective, and that services follow a trauma informed pathway approach to care.

A wide availability of different but evidence based interventions is important.

The availability of evidence based interventions is not the whole picture. It is arguable that outcomes for people receiving a diagnosis of personality disorder substantially depend on system behaviour across multiple service domains such as children`s services, education, social care, criminal justice, public health, public policy and primary care. People given the diagnosis of personality disorder have often experienced complex social and system failures early in life, leading to chronic difficulties in developing and maintaining sustainable adult identity and functioning which can affect how they engage with all services – not just those focused on mental health.

People diagnosed with a personality disorder experience complex social & system failures

As such, it is likely that changes in service provision within mental health services alone may not be the most significant factor in reducing the distress of this group of people. Unless we consider a whole system approach to care and support across the lifespan, limited results may be expected in terms of improved quality of life and reduced health service demand, even in the presence of mental health system capacity to deliver an adequate range of evidence based interventions.

Prescriptions for the development of specialist clinical services should therefore take place in the context of a sound understanding of the nature of complex social ‘wicked problems’ within the public realm.^{33, 34}

A trauma informed, formulation driven, whole system approach to care is necessary.

What works?

There is evidence that certain individual treatments do help (for example mentalization based therapy, schema therapy, and dialectical behaviour therapy) and for an emerging stepped care approach to treatment³⁵ but no one method appears to confer an advantage over another. A tool box approach designed around the core problems of the individual delivered skilfully by competent and compassionate clinicians may be as helpful for some people³⁶, with a clinician needing to be responsive to the current issues, using a flexible and holistic approach. Particularly important is a clear psychological formulation underpinning the service plan which is produced in collaboration with the individual receiving care. A psychological formulation is a written statement that provides an overview of the problem in understandable terms – it is a way of making sense of a complex set of difficulties. The focus on consistency, relationships and environments is aptly described in studies.^{37, 38, 39} These elements seem to be necessary conditions for the success of interventions that address the complexity of the distress that this group of people experience.

Livesley⁴⁰ identifies the five stages in the treatment process as; crisis management, containment, development of self-regulation, exploration of self and change (where needed), and finally integration and synthesis, by which point the person has both developed adaptive strategies for life in combination with necessary changes in life circumstances.

The Core Tenets of an Effective Intervention:

- developing a consistent therapeutic environment and network of services,
- a consistent and respectful therapeutic relationship in which a real sense of partnership can develop,
- psychologically informed practice,
- individual formulations,
- and a trained workforce

lie at the heart of service delivery.

When things go badly wrong and people end up in the criminal justice system?

Let's start seriously addressing mental health in the National Probation Service and Her Majesty's

Prison Service

Her Majesty's Prison and Probation Service (HMPPS) manages around 250,000 offenders; of those around 100,000 are deemed risky enough to be managed by the National Probation Service, the rest being managed by Community Rehabilitation Companies; around 85,000 of the 250,000 are in prison variously awaiting trial on criminal charges, awaiting sentencing or serving sentences.⁴¹ It has been estimated in surveys of prisoners that about 2/3 have a likely diagnosis of a personality disorder, and in a small study of a National Probation caseload the prevalence was around 50% (some of whom would have been in prison and some on community sentences)⁴². In 2016, there were 37,784 incidents of self-harm among prisoners – up from 9,967 from the previous year; 119 people killed themselves, which is the highest since records began in 1978⁴³. Many of these people would be given a diagnosis of personality disorder.

Despite these worrying figures, it is important to acknowledge that MOST people who could be given a diagnosis of Personality Disorder are NOT offenders. A small minority of these people have caused serious harm to others – and often themselves too – and, at least in the short to medium term, may do so again. They are detained in secure conditions until such time as they can access the means to change the situations they find themselves in. The root causes of their problems are similar to those of people who attract the diagnosis outside the criminal justice system – but often even more complex. The NHS and HMPPS Offender Personality Disorder pathway is a jointly designed, commissioned and delivered pathway of connected services mainly spanning prison and community / probation settings; it is aimed at men and women who are managed by the National Probation Service, and who also have very complex behavioural, psychological and social problems – in other words, likely to attract a diagnosis of 'personality disorder'. For men, they also have to be deemed to be at a high risk of committing further harmful offences. Around 37,000 people satisfy these criteria – 3,000 women and 33,000 men;⁴⁴ This pathway describes a new way of delivering services to a very complex and potentially challenging group; psychological formulation, either in combination or instead of psychiatric diagnosis, is more commonly used in an attempt to establish functional links between each individuals' life history and presenting problems, and the risk of future harm to the public. Generally, there is no need for a diagnosis, as individual holistic formulation of risk and need is at the heart of the pathway and drives the sentence plan. In addition, the focus is on using relationships and therapeutic environments as much as delivering evidenced psychological therapies. This pathway has two aims; improving psychological wellbeing and public protection, understanding that harmful behaviour is very often driven by trauma. The pathway concept is still being tested, but if found to be effective, describes a new model of addressing 'personality disorder' in the Criminal Justice System.

Working to overcome difficulties of engagement with this group of people is essential to optimise opportunities for treatment and hence offers the opportunity for them to engage in mainstream interventions. Negative assumptions can be made about the person's motivations and intentions, most often where there is a lack of understanding about the person's needs, and a failure to see their behaviours as having an adaptive function (e.g. self-protection due to previous experiences of psychological or physical harm from others). However, this does not mean that criminal behaviours are excusable, more that they are understandable in certain contexts.

Working effectively with this group of individuals generally necessitates a trauma informed approach which takes into account any biological vulnerabilities which can be exacerbated by traumatic experiences, thus interfering with a person's ability to manage their behaviours and emotions. Emerging neurological studies are beginning to reveal the extent to which early traumatic experiences can lead to physical changes in the brain. It is important to recognise, however, that people may not have experienced major trauma and yet still have needs best met through therapeutic approaches. In the absence of trauma histories, their needs may be particularly hard to recognise as they don't even attract the sympathy and concern which is often afforded to those with trauma histories. Many of them will have some measure of physically based developmental difficulties including foetal alcohol syndrome, general or specific intellectual disabilities, autistic spectrum disorders and/or attention deficit hyperactivity disorders.

The social environment will also impact through deprivation, poverty and lack of education and needs to be taken into account alongside any other factors which interfere with someone's ability to manage everyday life. The core tenets for effective treatment apply to this group of people as described previously.⁴⁵

**Use psychological formulation within a trauma informed approach
in criminal justice settings .**

Why it makes economic sense to provide appropriate treatment and support.

Let's use limited resources to the best effect

Balancing the budget in any health and social care community is imperative in public services today. Understanding the costs and benefits of different approaches to supporting people with personality difficulties remains an aspiration in many areas. Changing the way in which we respond to people's needs is sometimes deemed to be expensive, but offering inadequate help is costly too.

A recent report by King's College London⁴⁶ found that offering evidence based psychological interventions for people given a diagnosis of personality disorder costs an average of £751 more than existing services per episode. Participants in this study demonstrated an immediate reduction in self harming and suicidal behaviour alongside a reduction in violent incidents. These are all associated with extra costs to a range of public services, including within the NHS – for example in A&E attendances. And the economic and social cost of a single loss of life through suicide is estimated at £1.6 million⁴⁷.

The evidence that providing targeted support to this group of people is cost effective is out there. A Centre for Mental Health evaluation of a primary care-based service in City and Hackney clinical commissioning group providing psychological therapies and support for GPs to help people with complex needs, including those given a diagnosis of personality disorder found that it achieved higher recovery rates than the IAPT programme and that it reduced demand on GPs, A&E and outpatient departments. The cost of the service fell well below the NICE cost per QALY threshold of £20,000⁴⁸.



The way forward: What can we do to meet the challenges?

This consensus statement has been developed to prompt further discussions about the needs of people who may have been given a diagnosis of personality disorder. This statement does not attempt to review all that is known about the diagnosis of personality disorder nor is it intended to speak for everyone who may be experiencing difficulties in their everyday lives who could be diagnosed with a personality disorder. It is intended to highlight the general consensus of opinions of those who have been given a diagnosis of personality disorder alongside those of professionals who often come into contact with the people we are talking about whilst recognising that there will be multiple experiences of exclusion for people from minority ethnic, cultural and racial backgrounds and for those with disabilities.

This consensus statement has identified some changes that could be initiated now in advance of more long term plans. Longer term developments will need to be developed in response to the recommendations in this statement in order to develop the services that people given a diagnosis of personality disorder have a right to expect. Thorough research and evaluation of any changes needs to be undertaken and this may need to be funded in order to demonstrate their effectiveness. This consensus statement challenges those currently delivering services to make small, low cost or cost neutral changes that will make a difference. (See Table 1)

Critically, the mental health system isn't working as it needs to work. It's still based on the idea that most of the time we are mentally well but that some people 'cross a line' and become mentally ill. This set of ideas came from a time when, due to stigma, people were often motivated to dismiss or deny periods when they found life difficult, due to fears of being labelled by professionals as 'mad' and having their liberty taken away from them. We now know different; that psychological health changes over time, that all of us probably at times experience distress that means we need extra support, and that there often isn't a clear dividing line between the type of distress that requires treatment and the type that doesn't. People who end up with the diagnosis of personality disorder seem particularly ill served by this 'old style' of mental health care: they often don't benefit from medication, they often don't benefit from standard psychological treatment. The essential point is

that, for most, their problems are often so complicated that they're hard to help with mental health services alone.

We believe that helping people with these type of problems needs some new thinking from the system: about the importance of relationships and our early lives, about the skill mix of staff, about involving people in their care and about making sure that all agencies supporting the public work together in a way that fits the psychological health needs of the population. We believe that the evidence base is now so clear on the importance of these things that ignoring them is no longer an option. Carrying on as we have been will continue to incur unacceptable human and financial costs.

Finally, psychological wellbeing is a universal need. Many of the changes and potential solutions we have suggested in this statement would benefit everyone - not just those of us diagnosed with a personality disorder. We need to organise our public systems accordingly.

**Ignoring the needs of people
with a diagnosis of personality
disorder is no longer an option.**

WE NEED TO ACT NOW

Table 1

Meeting The Challenge: What Should People Given A Diagnosis Of Personality Disorder Expect?

Principle	What I expect now?	How might this work?	What can I expect in 5 years?
1 Shared ownership / Collaborative	My story is known by the people and understood by the people who need to know and they work together. I shouldn't have to keep repeating my story. I shouldn't be stigmatised by my experience	Public sector to establish a concordat with the individual at the centre to enable interagency communication. Evaluate Service Quality with communication as an outcome.	The Mental Health Dashboard will include quality measures relating to interagency communication and functioning alongside measures recording the effectiveness of communication between service users and providers
2 Formulation / Creative response/flexibly designed	A person centred, individualised trauma informed formulation of the reasons for my Psychological distress that I have co-produced	The System should agree on a core set of standardised tools and processes for assessing the competencies of all grades of staff in understanding formulation and in supporting the need for positive and safe relationships between staff and users of public services, appropriate to the nature of the service provided (eg education, criminal justice, health) paying particular attention to those who struggle to maintain relationships.	As a public health intervention, between the ages of 11 and 16, all children will have the option to create, with support, a formulation driven `personal passport outlining their personal preferences for psychological and emotional support, regardless of current contact with mental health services. This will be recognised as an official document by all public bodies. It would be used and/or developed at first point of contact with mental health services and continue to be developed over the lifespan to support population psychological health and continuity of care Digital technologies will be central to this development.
3 Relational Practice /Connected	People supporting me understand that relationships are central to my life and the relationship with public services plays a part in keeping me safe.	All organisations within the Public Sector develop a simple multiagency guide to help support relational practice and the development of psychologically safe and supportive service relationships. Psychologically informed environments should be developed with strong clinical leadership to overcome difficulties and to offer appropriate support and supervision	All public sector organisations have integrated into their governance processes key performance indicators measuring the quality of psychologically informed practice.

4 Sustainable Long Term Planning	I have a right to be able to access a lifelong service pathway which is age appropriate for my psychological health.	The development of a Pathway for psychological health and well-being spanning prevention, and intervention across all public agencies.	Cross party communication and consensus to develop an integrated Psychological health pathway across the lifespan working with all professional bodies and aligned with other long term government strategies. This should be subject to public consultation and engagement and be integrated into workforce planning.
5 Right Treatment / right place / right time	I have the right to receive evidence based treatments delivered from a suitable venue in a timely fashion from services that offer an integrated approach to my care throughout my life.	Co produced training for evidence based intervention should be offered to staff. Regular supervision should be available to all staff delivering evidence based intervention. Meaningful outcomes should be collated by services. Monitoring of instances of harm due to poor service delivery ("iatrogenic harm") should be routine.	Fragmentation of Service delivery is reduced across the life course. Staff possess appropriate skills and competencies in evidence based treatment. Incidences of iatrogenic harm are reduced.
6 Supportive / competent / reflective staff	Competent and supportive staff	Staff are more self-reflective and supported.	Services will have developed a culture of compassion and reflection to support Staff.
7 Culture change/Changes to the label "Personality Disorder"	I have a right to be treated with respect and offered appropriate interventions according to need rather than it being based solely on a diagnostic label	High level work undertaken to review the use of the diagnostic label to offer recommendations for change across agencies. Actively engage in mechanisms to bring about attitude change i.e media campaigns	Greater understanding amongst the general public and changes in the culture of services and the attitudes which staff have towards people given a diagnosis of Personality Disorder.

Appendix A

Results of Personality Disorder Consensus Survey December 2016

The survey revealed four major themes as described in the consensus statement. These themes are described in more detail below.

1. Factors that were helpful in promoting satisfaction with services were:-

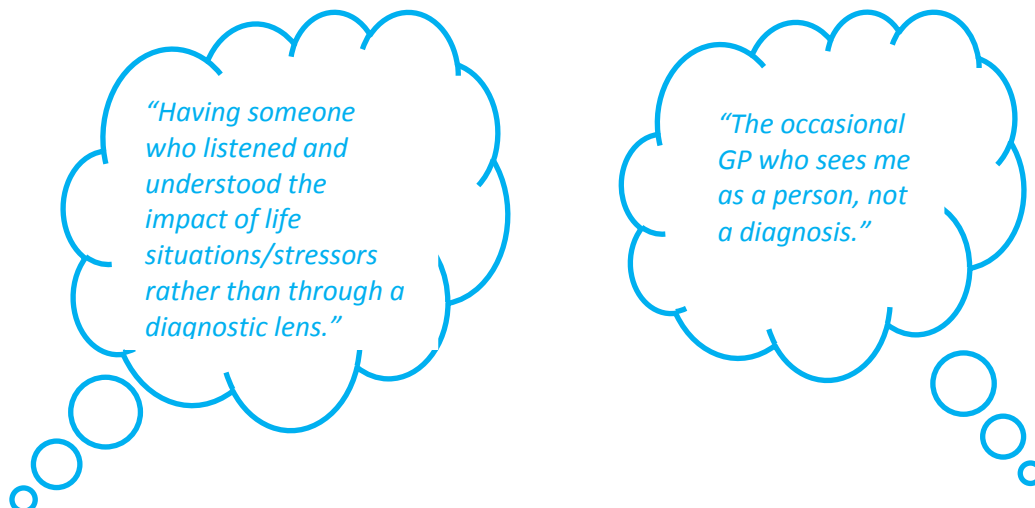
1.1. continuity of professionals

70 participants reported the importance of familiarity; and having a consistent staff member helped them to feel understood and supported.



1.2. Willingness of professionals to listen:

Participants reported the importance of professionals looking beyond a diagnostic label and a willing to learn about what was going on for them as an individual as key .



1.3. Right match for services:

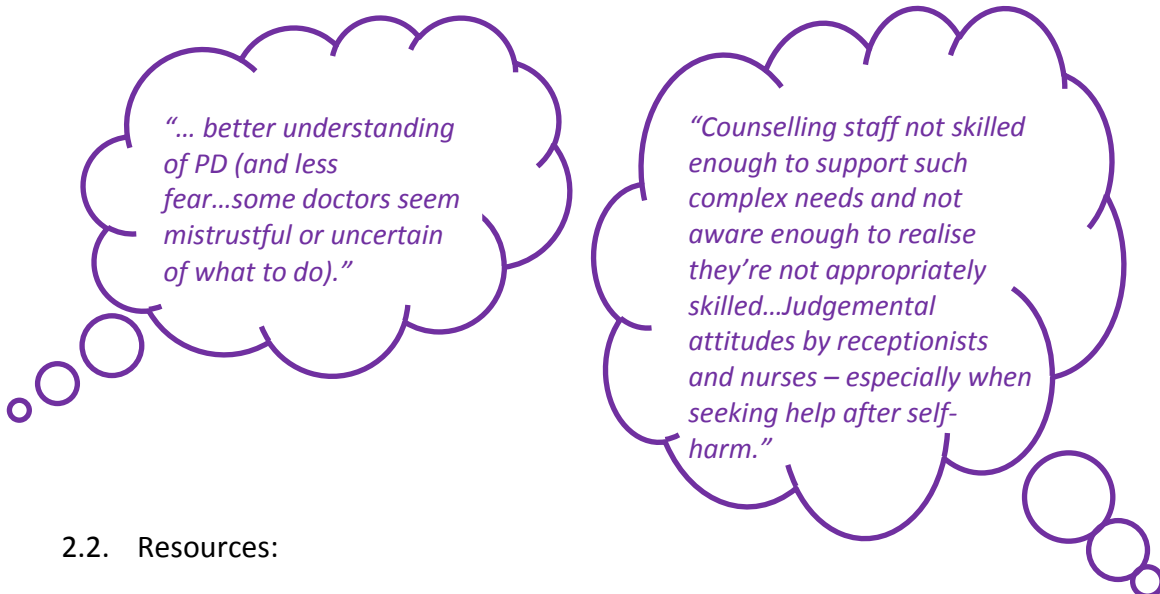
Participants reported finding it helpful when they were quickly signposted to other support services that were better equipped to meet their needs.



2. **Factors increasing confidence in services** included:-

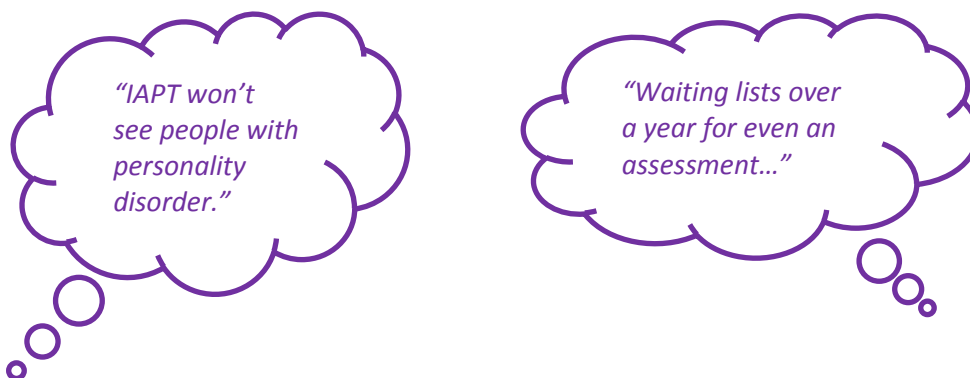
2.1. Staff competence and knowledge:

Participants wished to be seen by knowledgeable and competent staff and suggested that professionals could have more training to understand their difficulties better and hence be better equipped to support them.



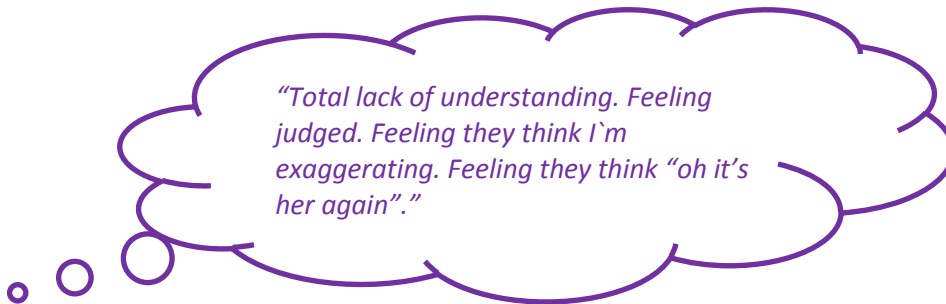
2.2. Resources:

Inadequate resources led to feelings of frustration, particularly around long wait times and limited access to some services.



2.3. Professionals ability to understand:

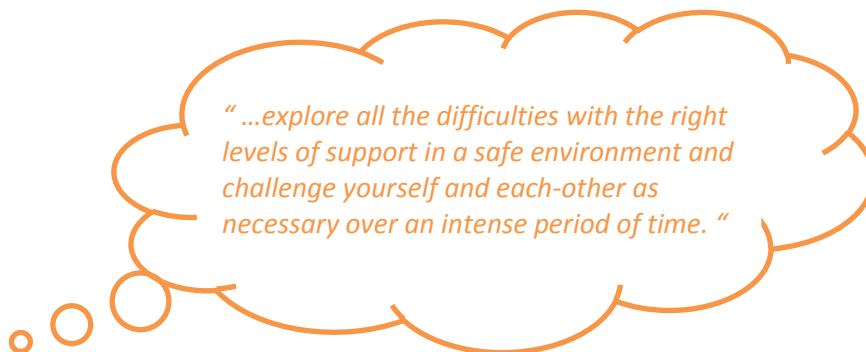
Professionals lack of understanding of participants was highlighted as a difficulty.



3. Participants highlighted **the importance of being able to connect with others** while accessing services.

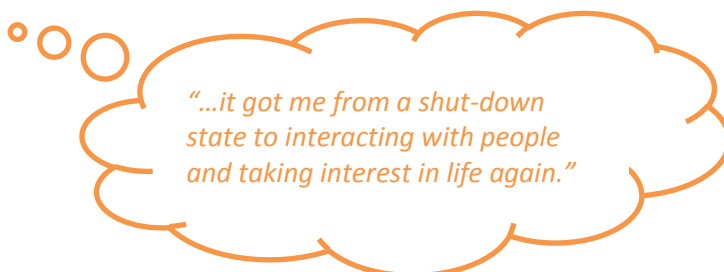
3.1. Normalising:

Hearing other group members talk about their psychological difficulties enabled participants to connect with each-other through shared experiences, which normalised their own.



3.2. Increasing social contact:

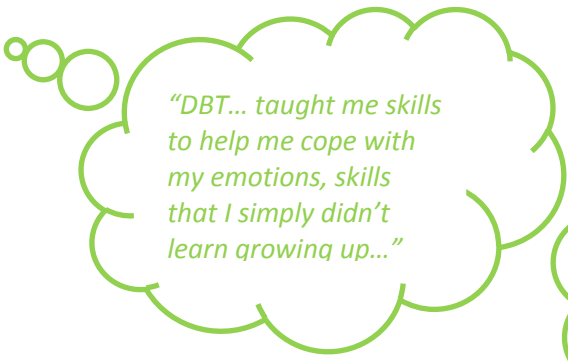
Some respondents spoke about group therapy interventions as a valued opportunity to socialise with others and give them hope in life again.



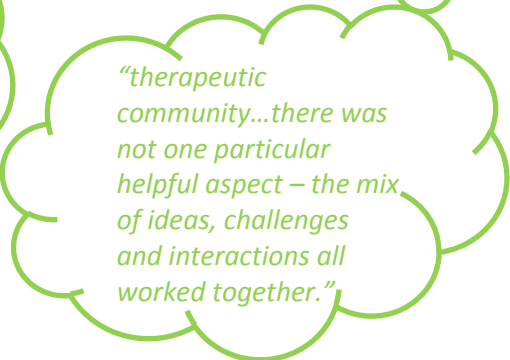
4. **Future Support:** Participants stated that utilising other voluntary and professional sectors would be beneficial for their journey.

4.1 Choice of interventions:

Participants stated that intervention choice was crucial to their experience. Particular references were made to Dialectical Behaviour Therapy and therapeutic communities. Both were described as a comprehensive and effective treatment in helping them in their journey.



"DBT... taught me skills to help me cope with my emotions, skills that I simply didn't learn growing up..."

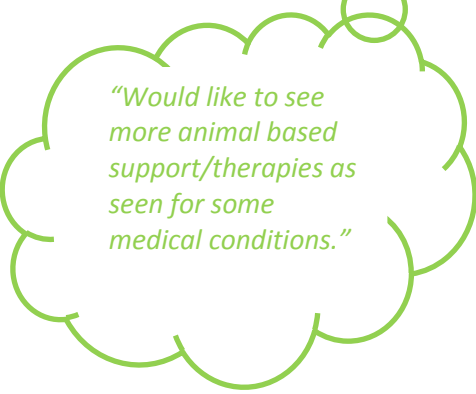


"therapeutic community...there was not one particular helpful aspect – the mix of ideas, challenges and interactions all worked together."

- 4.2 Creative therapy: groups such as art and animal therapy were mentioned alongside the benefits of exercise, in particular walking groups.



"Art therapy should be more easy to access."



"Would like to see more animal based support/therapies as seen for some medical conditions."

4.3 Collaboration with other services:

Participants wanted services to join together more often and work together to provide a comprehensive and effective intervention that is long-lasting.



"It is really important that mental health services start to work with other organisations without dominating them..."

Appendix B

Adverse Childhood Experiences (ACEs)

Stressful events occurring during childhood that directly affect a child (e.g. child maltreatment) or affect the environment in which they live (e.g. growing up in a house where there is domestic violence)

How many adults in England have suffered each ACE?

CHILD MALTREATMENT



Verbal abuse
18%



Physical abuse
15%



Sexual abuse
6%

CHILDHOOD HOUSEHOLD INCLUDED



Parental separation
24%



Domestic violence
13%



Mental illness
12%



Alcohol abuse
10%

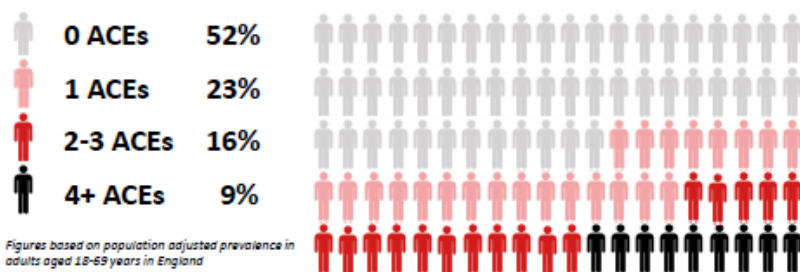


Drug use
4%



Incarceration
4%

For every 100 adults in England 48 have suffered at least one ACE during their childhood and 9 have suffered 4 or more



ACEs increase individuals' risks of developing health-harming behaviours

Compared with people with no ACEs, those with 4+ ACEs are:

- 2 times more likely to currently binge drink and have a poor diet
- 3 times more likely to be a current smoker
- 5 times more likely to have had sex while under 16 years old
- 6 times more likely to have had or caused an unplanned teenage pregnancy
- 7 times more likely to have been involved in violence in the last year
- 11 times more likely to have used heroin/crack or been incarcerated

Preventing ACEs in future generations could reduce levels of:



Early sex
(before age 16)
by 33%



Unintended teen pregnancy
by 38%



Smoking
(current)
by 16%



Binge drinking
(current)
by 15%



Cannabis use
(lifetime)
by 33%



Heroin/crack use
(lifetime)
by 59%



Violence victimisation
(past year)
by 51%



Violence perpetration
(past year)
by 52%



Incarceration
(lifetime)
by 53%



Poor diet
(current; <2 fruit & veg portions daily)
by 14%

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References

1. *The International Classification of Diseases Version 11*. World Health Organisation
2. *The Diagnostic and Statistical Manual of Mental Disorders*. American Psychiatric Association
3. Lancet Editorial (2016). The Health Crisis of Mental health Stigma. *The Lancet* Vol 387 March 12.
4. Lam, D. C. K., Poplavskaia, E. V., Salkovskis, P. M., Hogg, L. I. and Panting, H., 2015. Forthcoming. An experimental investigation of the impact of personality disorder diagnosis on clinicians: can we see past the borderline? *Behavioural and Cognitive Psychotherapy*. 44 (03) 361-374.
5. Bodner, E., Cohen-Fridel, S., Mashiah, M., Segal, M., Grinshpoon, A., Fischel, T. & Lancu, L. (2015) The attitudes of psychiatric hospital staff toward hospitalization and treatment of patients with borderline personality disorder. *BMC Psychiatry* 15:2, 1-12. DOI 10.1186/s12888-014-0380-y
6. NIMHE (2003) *Personality disorder: no longer a diagnosis of exclusion*. Department of Health.
7. Herman, J. (2001). *Trauma and Recovery (2nd Ed)*. London: Pandora
8. Van der Kolk, B. (2014). *The Body Keeps the Score*. USA: Viking, Penguin Group.
9. Huang Y, Kotov R, de GG, et al. DSM-IV personality disorders in the WHO World Mental Health Surveys. *BrJPsychiatry* 2009; **195**(1): 46-53.
10. Newton-Howes G, Tyrer P, Anagnostakis K, et al. The prevalence of personality disorder, its comorbidity with mental state disorders, and its clinical significance in community mental health teams. *Social psychiatry and psychiatric epidemiology* 2010; **45**(4): 453-60.
11. Singleton N, Meltzer H, Gatward R, Coid J, & Deasy D (1997) *Psychiatric Morbidity Among Prisoners: A summary report*. Office for National Statistics & Department of Health
12. Moran P, Romaniuk H, Coffey C, et al. The influence of personality disorder on the future mental health and social adjustment of young adults: a population-based, longitudinal cohort study. *The lancet Psychiatry* 2016; **3**(7): 636-45.
13. Quirk SE, Berk M, Chanen AM, et al. Population prevalence of personality disorder and associations with physical health comorbidities and health care service utilization: A review. *Personality Disorder* 2016; **7**(2): 136-46.
14. Gerlach G, Loeber S, Herpertz S. Personality disorders and obesity: a systematic review. *Obes Rev* 2016; **17**(8): 691-723.

15. Fok ML, Hayes RD, Chang CK, Stewart R, Callard FJ, Moran P. Life expectancy at birth and all-cause mortality among people with personality disorder. *Journal of Psychosomatic Research* 2012; **73**(2): 104-7.
16. Bjorkenstam E, Bjorkenstam C, Holm H, Gerdin B, Ekselius L. Excess cause-specific mortality in in-patient-treated individuals with personality disorder: 25-year nationwide population-based study. *The British journal of psychiatry : the journal of mental science* 2015; **207**(4): 339-45.
17. Hayward M, Slade M, Moran PA. Personality disorders and unmet needs among psychiatric inpatients. *PsychiatrServ* 2006; **57**(4): 538-43.
18. Sanatinia R, Middleton SM, Lin T, Dale O, Crawford MJ. Quality of physical health care among patients with personality disorder. *Personality and mental health* 2015; **9**(4): 319-29
19. *Meeting the Challenge, Making a difference* .Department of Health 2014
20. ¹¹ National Institute for Health and Clinical Excellence (2009) *Borderline Personality Disorder: Treatment and Management*. London: NICE.
21. National Institute for Health and Clinical Excellence (2009) *Antisocial Personality Disorder: Treatment, Management and Prevention*. London: NICE.
22. *The Five Year Forward View for Mental Health* (2016) *Mental Health Taskforce Report*
23. Kim-Cohen J, Caspi A, Moffitt T.T, Harrington H, Milne B.J, Poulton R (2003) Prior Juvenile Diagnosis in Adults with Mental Disorders: a developmental follow-back of a prospective-longitudinal cohort. *Archives of General Psychiatry* 60(7):709-17
24. Filetti, V.J., Anda, R.F., Nordenberg, D., Williamson, D.F., Spitz, A.M., Edwards, V., Koss, M. and Marks, J. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. *American Journal of Preventive Medicine*, 14(4), pp.245-258.
25. Bellis, M.A., Lowey, H., Leckenby, N., Hughes, K. and Harrison, D. (2013). Adverse childhood experiences: retrospective study to determine their impact on adult health behaviours and health outcomes in a UK population. *Journal of Public Health*, 36(1), pp.81-91.
26. Bellis, M.A., Hughes, K., Leckenby, N., Perkins, C. and Lowey, H. (2014). National household survey of adverse childhood experiences and their relationship with resilience to health-harming behaviors in England. *BMC medicine*, 12(1), p.72.

27. Real Life Research (2015). An Evaluation of REACH: Routine enquiry into adversity in childhood. *Independent evaluation of work commissioned by Blackburn local authority public health team.*
28. Pearce, J., Murray, C., Larkin, W., and Simpson-Adkins, G. *Asking about Childhood Adversity and Trauma: Experiences of professionals trained to routinely enquire about child adversity.* Manuscript submitted for publication
29. Sharp C & Fonagy P (2015) Practitioner Review: Borderline Personality Disorder in Adolescence – recent conceptualization, intervention, and implications for clinical practice. *Journal of Child Psychology and Psychiatry* 56:12 p1266-1288
- 30 Fonagy P, Speranza M, Luyten P, Kaess M, Hessels C & Bohus M (2015) ESCAP Expert Article: Borderline Personality disorder in adolescence: An expert research review with implications for clinical practice. *European Child Adolescent Psychiatry* 24: 1307-1320
- 31 Chanen A.M, Berk M & Thompson K (2016) Integrating Early Intervention for Borderline Personality Disorder and Mood Disorders *Harvard Review of Psychiatry* vol 24 no 5 p330-341
- 32 Evans S, Sethi F, Dale O, Stanton C, Sedgwick R, Doran M, Shoolbred L, Goldsack S and Haigh R (2017) Personality Disorder Service Provision: A Review of the Recent Literature (In submission)
- 33 Grint K. (2008) Wicked Problems and Clumsy Solutions: the role of leadership. *Clinical Leader Vol 1 No 11*
34. Horne R.E & Weber R.P. (2007) *New Tools for Resolving Wicked Problems.*
http://www.strategykinetics.com/New_Tools_For_Resolving_Wicked_Problems.pdf
- 35 Choi-Kain, L W. ; Albert, E B. ; Gunderson, J G. (2016) Evidence-Based Treatments for Borderline Personality Disorder: Implementation, Integration, and Stepped Care *Harvard Review of Psychiatry.* Vol 24, no 5, p342-356
36. Bateman A.W, Gunderson J,& Mulder R (2015) Treatment of personality disorder *The Lancet* Vol 385, no 9969, p 735-743
37. Benefield N. (in submission)
- 38 Haigh R (2013) The Quintessence of a Therapeutic Environment. *The International Journal of Therapeutic Communities.* Vol 34, N01, p6-15.
- 39 Johnson R & Haigh R, editors (2012) . "Complex trauma and its effects: perspectives on creating an environment for recovery" Brighton: Pavilion
40. Livesley W.J. (2005) Principles and Strategies for treating Personality Disorder. *Canadian Journal of Psychiatry.* Vol 50, p 442-450

41. Ministry of Justice statistical bulletin (2016). Offender Management Statistics Quarterly: January to March 2016. Probation Q1: 2016.
<https://www.gov.uk/government/statistics/offender-management-statistics-quarterly-january-to-march-2016> [1 August 2016]
42. Brooker, Charlie, Sirdifield, Coral, Blizard, Robert, Denney, David, Pluck, Graham. (2012) *Probation and mental illness*. Journal of Forensic Psychiatry and Psychology, 23 (4). pp. 522-537
43. Ministry of Justice (2017) *Safety in Custody Statistics Bulletin, England and Wales, Deaths in prison custody to December 2016, Assaults and Self-Harm to September 2016*
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/595797/safety-in-custody-quarterly-bulletin.pdf
44. Skett, S Goode, I, Barton, S. 2017. A joint NHS and NOMS offender personality disorder pathway: a perspective of 5 years of operation. Criminal Behaviour and Mental Health. Online. DOI: 10.1002/cbm.2026
- 45 *The Offender Personality Disorder Pathway* (2015) National Offender Management Service and Department of Health
46. Zala D & McCrone P (2017) The cost-effectiveness of Improving Access to Psychological Therapies (IAPT) in severe mental illness: a decision analytical model using routine data (2017). Zala & McCrone Kings College London (in preparation)
- 47 Knapp M and Lemmi V (2013) 'The economic case for better mental health', *Annual Report of the Chief Medical Officer 2013, Public Mental Health Priorities: Investing in the Evidence*.
- 48 Parsonage M, Hard E & Rock B (2014) Managing Patients with Complex Needs. Centre for mental Health <https://www.centreformentalhealth.org.uk/complex-needs-report>