## Cambridgeshire

# Joint Strategic Needs Assessment (JSNA)

### AUTISM, PERSONALITY DISORDERS AND DUAL DIAGNOSIS

## 2014

This report was commissioned from Solutions for Public Health (SPH) by the Public Health Team, Cambridgeshire County Council. The contents are based upon the work undertaken by SPH, with support and contributions from the Cambridgeshire Adult and Older Peoples Mental Health JSNA Steering Group and editorial amendments and additions made by the Public Health Team at Cambridgeshire County Council.

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### 1. Executive summary

This joint strategic needs assessment reviews the mental health needs of people of working age with autism spectrum conditions, personality disorder and dual diagnosis, living in Cambridgeshire.

It is important to be clear that about the differences between mental wellbeing (or general mental health), and mental illness.

In this document we refer to both using the definitions below:

**Mental wellbeing (or mental health):** There are many different definitions of mental wellbeing but they generally include factors known to promote mental health such as: life satisfaction, optimism, self-esteem, mastery and feeling in control, having a purpose in life, and a sense of belonging and support. Good mental health is not simply the absence of diagnosable mental health problems, although good mental health is likely to help protect against the development of many such problems.

**Mental illness or disorder:** Mental illness or disorder refers to a diagnosable condition that significantly interferes with an individual's cognitive, emotional or social abilities e.g. depression, anxiety, and schizophrenia.

The three conditions which are the focus of this report are all diagnosable mental illnesses. However, this document also highlights some of the factors which overall may increase our risk of poorer mental health. These include social factors such as deprivation, social support, long term conditions, employment, and homelessness.

The most common mental disorders are depression and anxiety. The three conditions this report looks at are all less common mental health disorders. The mental health needs of adults with Autistic Spectrum Condition (ASC), personality disorder and dual diagnosis are complex. People with these conditions often experience comorbidities (both mental and physical), behaviour difficulties, social exclusion and unemployment. Some may have contact with the criminal justice system, as either victims of crime or offenders. Their mental health needs of carers.

**Autism Spectrum Conditions (ASC)** are a group of complex brain development disorders<sup>1</sup> that affect people in the way they communicate, relate to others and make sense of the world around them. Those with ASC often share certain characteristics; however as the condition moves along the spectrum it varies in severity and affects people in different ways.

The main issues facing people with the condition are:

- Problems with social interaction and communication
- Restricted and repetitive patterns of thought, interests and physical behaviours,
- A resistance to change, and having restricted interests.

<sup>&</sup>lt;sup>1</sup> World Health Organization (WHO) - <u>http://www.who.int/features/qa/85/en/</u>

Conditions covered by the spectrum include Asperger syndrome and childhood autism. However there is a move towards using a more encompassing umbrella diagnosis rather than diagnosing separating conditions. It is believed that this better reflects the current state of knowledge about autism<sup>2</sup>, as it is felt that there is currently not enough research to show definite distinctions between the different conditions<sup>3</sup>.

**Personality disorders** are conditions in which an individual differs significantly from an average person, in terms of how they think, perceive, feel or relate to others. Changes in how a person feels and distorted beliefs about other people can lead to highly unusual behaviour, which can be distressing and may upset others.

People with *dual diagnosis* have a mental health problem and also misuse drugs or alcohol. The substance misuse may be related to the mental health problem: some people use drugs or drink excessively in order to manage symptoms of mental illness such as anxiety or depression. Alternatively, mental illness may have been triggered or exacerbated by drug and alcohol use.

This report starts by describing the population of Cambridgeshire, with particular emphasis on the adult population and the factors which increase the risk of poor mental health. It goes on to estimate how many people in Cambridgeshire, both now and in the future, have and will have the disorders covered by this report. The report then describes the present pattern of services available in Cambridgeshire for people with these disorders, and it reports findings from research about the interventions which, if used early in the course of illness, may reduce their severity. The report then summarises the results of engagement with service users, carers and providers, before setting out its key findings.

The difficulties with securing data on NHS activity meant that the report has adopted a qualitative approach. There are also other sources of information which were not available or accessible during this project, and these mean there are limits to the conclusions we are able to draw. These include details of where people with mental health problems live, the exact nature of all clinical and social care services provided locally and the outcomes of service interventions. It has not been possible therefore to assess the degree of correlation between needs and access to services, and whether services are delivered to national standards.

### **Key Facts**

- 1. The population of Cambridgeshire is expected to grow by 19% between 2012 and 2026, including growth in nearly all age-groups and all local authority areas.
- 2. Cambridgeshire's population is more affluent and less ethnically diverse than that of England, but social isolation is no less common.
- 3. Most risk factors for poor mental health show similar patterns of prevalence across Cambridgeshire, though in some cases the Cambridgeshire population shows a

<sup>&</sup>lt;sup>2</sup> American Psychiatric Association, Autism Spectrum Disorder -<u>http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf</u>

<sup>&</sup>lt;sup>3</sup> The National Autistic Society - www.autism.org

lower risk profile. There are also areas within the county where risk factors are concentrated, such as Fenland.

- 4. For the specific conditions considered in this report, by 2026, there are expected to be about 2,000 people in the County with borderline personality disorder, about 1,600 with anti-social personality disorder and about 5,100 with autism spectrum conditions. Projecting the prevalence of dual diagnosis is more complicated because the age-specific prevalence is not constant. No projected prevalence of dual diagnosis is available, but the rising prevalence of excessive drinking suggests that it is likely to become more common amongst a proportion of this group<sup>4</sup>.
- 5. An increase in prevalence of common mental health disorders, as well as those conditions specific to this report, is predicted across all Cambridgeshire districts, with growth in numbers concentrated in Cambridge City especially.
- 6. The number of people affected by mental illness in Cambridgeshire is expected to increase in line with the population. In Cambridgeshire, many people with depression have not been diagnosed and recorded by their primary care teams, which reflects a national trend. This means they cannot receive the treatment and support they need. This suggests that there is unmet mental health need within the population. In addition, depression occurs in people with ASC, personality disorder and dual diagnosis, so this under-diagnosis of depression is relevant to their needs.
- 7. The main concerns of service users and carers reported to us were:
  - Service delivery
  - Organisational challenges
  - Coordination of services
  - Safeguarding of vulnerable people
  - Access to services
  - Transition between services
  - Continuity of relationships
  - Culture and equity
  - Physical health and mental health
  - Carers needs

Service improvement ideas from service users and carers included more help with practical things, such as maintaining relationships, applying for benefits, and a focus on the positives rather than the diagnosis. Community support and signposting for where to go for help, ideas or friendship were also considered important. Information and training for families and carers as well as those with mental health disorders, and seeing the same health professional consistently were also suggested. Some of the case studies in the full JSNA illustrate innovative ways to improve services and respond to some of these suggestions.

### Key findings

1. Due to an increasing population there will be an increase in the number of people with these mental health disorders within a few years. However, the resources available from statutory agencies for health services given the current financial restraints will at best

<sup>&</sup>lt;sup>4</sup> Home Office. The Government's Alcohol Strategy. March 2012. www.gov.uk/government/publications/alcohol-strategy

remain the same, requiring the development of new service models to meet need. A holistic approach is vital.

- 2. National guidance in the form of Clinical Guidelines and Quality Standards published by NICE describe in detail what patients should receive from NHS and social services. Existing service specifications from commissioners describe what should be available from NHS mental health services, though not in the case of Autistic Spectrum Conditions. However, the extent to which national guidance and local service specifications are followed in practice was not reviewed as part of this JSNA. This should form part of a future work programme.
- 3. We found no reliably evaluated early interventions for people with ASC, personality disorder and dual diagnosis published since the most recent NICE guidance. Therefore the most recent NICE guidance should be used as the basis for early intervention work.
- 4. Adults with severe mental illness have a substantially reduced life expectancy due to both mental and physical ill health with a significant proportion of excess deaths being associated with physical conditions. A proportion of those within the specific conditions considered in this report are likely to have severe mental illness. In addition, there is often inequality of access to health services for physical illness for people who use mental health services. People with mental illness need equal access in order to improve their physical health problems and reduce their risk factors.
- 5. For adults with autism, a high-quality diagnostic service is available from CPFT. However, services to support adults with autism and their carers in the community are sometimes fragmented and difficult to access. The recently published quality standard<sup>5</sup> for autism (January 2014) is a good basis on which to review the commissioned service specification and to review the services provided for adults with autism.
- 6. There are strong indications of problems in services for people with dual diagnosis. There are examples from both service providers and service users which suggest that sometimes, neither the substance misuse service nor mental health services are apparently willing to take on patients with more severe dual diagnoses, with no system for adjudication in such cases. As a result, some clients are left with no service.
  - a. Commissioners should consider a review of services for dual diagnosis. An option, recommended by stakeholders, is to establish a jointly funded single service for those who had more severe dual diagnoses, which would take responsibility for those neither service would itself treat. This service would either treat the client, or assign them to one or other service.
  - b. NICE recommends that "Specialist substance misuse services should work closely with secondary care mental health services to develop local protocols derived from this guideline for adults and young people with psychosis and coexisting substance misuse. The agreed local protocols should set out responsibilities and processes for assessment, referral, treatment and shared care across the whole care pathway<sup>6</sup>." Although such a protocol exists in Cambridgeshire, its implementation appears to be incomplete.

<sup>&</sup>lt;sup>5</sup> Autism. QS51, 2014. <u>http://guidance.nice.org.uk/QS51</u>

 <sup>&</sup>lt;sup>6</sup> Psychosis with coexisting substance misuse: Assessment and management in adults and young people. CG120, 2011. <u>www.nice.org.uk/CG120</u>

- 7. Adults with mental disorders, including personality disorder, dual diagnosis and autism, sometimes experience mental health crisis and need help quickly to stop them harming themselves or others. The Crisis Care Concordat<sup>7</sup> is aimed at making sure that people experiencing a mental health crisis receive an appropriate emergency mental health service. It reflects a new requirement for the NHS that "every community has plans to ensure no one in mental health crisis will be turned away from health services"<sup>8</sup>. There should be local implementation of the Crisis Care Concordat to ensure that adults in mental health crisis are able to recover, and that admissions to hospital or to prison might be avoided.
- 8. No information on activity levels and expenditure patterns by the main NHS mental health service provider in Cambridgeshire was available within the timescale of this report. This impedes service planning and evaluation by commissioners. It also limited the extent to which we can comment on patterns of service delivery. The routinely collected anonymised national minimum dataset should be available in a timely and accessible format to providers and commissioners of mental health services.

<sup>&</sup>lt;sup>7</sup> Department of Health and Home Office <u>Mental Health Crisis Care Concordat - Improving outcomes for people</u> <u>experiencing mental health crisis</u> February 2014

<sup>&</sup>lt;sup>8</sup> Department of Health The Mandate: A mandate from the government to NHS England: April 2014 to march 2015. <u>https://www.gov.uk/government/publications/nhs-mandate-2014-to-2015</u>

### 2. Introduction

This section sets out the purpose of this report, describes the nature of the mental health problems considered here, provides context to the report and outlines the structure of the rest of the document.

This needs assessment reviews the mental health needs of people of working age with autism spectrum conditions, personality disorder and dual diagnosis, living in Cambridgeshire.

Its aim is to assess whether services for people with these conditions are meeting current and future need.

Its objectives are to:

- To estimate current need and predict future needs based on demographic modelling.
- Identify the assets and current service provision for mental health for people with the conditions of interest in Cambridgeshire.
- Engage with service users and carers to explore the patient perspective of existing services and assets, to understand whether services are accessible and appropriate.
- Quantify local activity and spending on treatment of the mental disorders covered in this report.
- Identify evidence-based approaches to prevention and early intervention.

**Autism spectrum Conditions (ASC)** are a group of complex brain development disorders<sup>9</sup> that affect people in the way they communicate, relate to others and make sense of the world around them. Those with ASC often share certain characteristics; however as the condition moves along the spectrum it varies in severity and affects people in different ways.

The main issues facing people with the condition are:

- Problems with social interaction and communication; including problems understanding and being aware of other people's emotions and feelings. The condition can also include delayed language development and an inability to start conversations or take part in them properly.
- Restricted and repetitive patterns of thought, interests and physical behaviours, including making repetitive physical movements, such as hand-tapping or twisting, and becoming upset if these set routines are disrupted.
- A resistance to change, and having restricted interests.

People with ASC may also commonly experience difficulty in expressing flexibility and have altered sensitivity to sounds, touch, tastes, smells, light or colour<sup>10</sup>.

Disorders covered by the spectrum include Asperger syndrome and childhood autism. However there is a move towards using a more encompassing umbrella diagnosis rather than diagnosing these separate conditions. It is believed that this better reflects the current

<sup>&</sup>lt;sup>9</sup> World Health Organization (WHO) - http://www.who.int/features/qa/85/en/

<sup>&</sup>lt;sup>10</sup> National Institute for Health and Care Excellence (2014) Autism: recognition, referral, diagnosis and management of adults on the autism spectrum: NICE Clinical guidance 142

state of knowledge about autism<sup>11</sup>, as it is felt that there is not enough research to show definite distinctions between the different conditions<sup>12</sup>.

Those with ASC have differing levels of cognitive ability ranging from profound intellectual disability in some people, to above average intellectual ability in others<sup>13</sup>. Around 70% of those with ASC also have at least one other (often unrecognised) physical or mental health problem, such as sleep problems, epilepsy, or depression<sup>14</sup>, and although some people with ASC are able to live relatively independent lives others may need a lifetime of specialist support<sup>15</sup>.

**Personality disorders** are conditions in which an individual differs significantly from an average person, in terms of how they think, perceive, feel or relate to others<sup>16</sup>. Changes in how a person feels and distorted beliefs about other people can lead to highly unusual behaviour, which can be distressing and may upset others.

The main symptoms of personality disorders are:

- Being overwhelmed by negative feelings such as distress, anxiety, worthlessness or anger.
- Avoiding other people and feeling empty and emotionally disconnected.
- Difficulty managing negative feelings without self-harming (for example, abusing drugs and alcohol, or taking overdoses) or, in rare cases, threatening other people
- Odd behaviour.
- Difficulty maintaining stable and close relationships, especially with partners, children and professional carers.
- Sometimes periods of losing contact with reality.

Symptoms typically get worse with stress. People with personality disorders often have other mental health problems, especially depression and substance misuse.

Several different types of personality disorder are recognised. They can be broadly grouped into one of three clusters - A, B or C - which are summarised below<sup>17</sup>. More detail on borderline personality disorder and antisocial personality disorder is provided at appendix 3.

#### Cluster A personality disorders

A person with a cluster A personality disorder tends to have difficulty relating to others and usually shows patterns of behaviour most people would regard as odd and eccentric. Others may describe them as living in a fantasy world of their own.

An example is paranoid personality disorder, where the person is extremely distrustful and suspicious.

<sup>&</sup>lt;sup>11</sup> American Psychiatric Association, Autism Spectrum Disorder -<u>http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf</u>

<sup>&</sup>lt;sup>12</sup> The National Autistic Society - www.autism.org

<sup>&</sup>lt;sup>13</sup> National Institute for Health and Care Excellence (2014) Autism: NICE Quality Standard 51 <sup>14</sup> National Institute for Health and Care Excellence (2014) Autism: NICE Quality Standard 51

<sup>&</sup>lt;sup>14</sup> National Institute for Health and Care Excellence (2014) Autism: NICE Quality Standard 51

<sup>&</sup>lt;sup>15</sup> The National Autistic Society - http://www.autism.org.uk/

<sup>&</sup>lt;sup>16</sup> <u>www.nhs.uk/conditions/personality-disorder/pages/definition.aspx</u> (accessed 31/03/2014)

<sup>&</sup>lt;sup>17</sup> Mental health foundation www.mentalhealth.org.uk

#### Cluster B personality disorders

A person with a cluster B personality disorder struggles to regulate their feelings and often swings between positive and negative views of others. This can lead to patterns of behaviour others describe as dramatic, unpredictable and disturbing.

An example is borderline personality disorder, where the person is emotionally unstable, has impulses to self-harm and intense and unstable relationships with others. Antisocial personality disorder is also part of cluster B.

#### Cluster C personality disorders

A person with a cluster C personality disorder struggles with persistent and overwhelming feelings of anxiety and fear. They may show patterns of behaviour most people would regard as antisocial and withdrawn.

An example is avoidant personality disorder, where the person appears painfully shy, socially inhibited, feels inadequate and is extremely sensitive to rejection. The person may want to be close to others, but lacks confidence to form a close relationship.

People with *dual diagnosis* have a mental health problem and also misuse drugs or alcohol. The substance misuse may be related to the mental health problem: some people use drugs or drink excessively in order to manage symptoms of mental illness such as anxiety or depression. Alternatively, mental illness may have been triggered or exacerbated by drug and alcohol use. In any case, the assessment and treatment of each problem needs to reflect, and may be materially affected by, the co-existence of the two.

#### 2.1 National context and policy drivers

There are a range of national policy drivers which support and provide a context for local strategies. Critically the context we are now working in is one of considerable financial constraint.

The *National Service Framework*<sup>18</sup> (NSF) published in 1999 by the Department of Health. The NSF was a ten year programme designed to set consistent and measurable standards for the delivery of mental healthcare across England and Wales and the framework within which health and social care services were required to work.

In later years, the previous Government's mental health policy became more focused on themes which promoted social inclusion and the individual's engagement with their communities and working life, and which challenged inequality and stigma. At the end of ten years the NSF was replaced by *New Horizons: A Shared Vision for Mental Health*, published in December 2009<sup>19</sup>. *New Horizons* was a cross-government programme of action to improve the mental health and wellbeing of the population. It aimed to:

- Improve the mental health and wellbeing of the population.
- Improve the quality and accessibility of services for people with poor mental health.

<sup>&</sup>lt;sup>18</sup> Mental Health National Service Framework (NSF) Department of Health 1999

<sup>&</sup>lt;sup>19</sup> New Horizons: A Shared Vision for Mental Health. Department of Health 2009

*New Horizons* describes factors that affect wellbeing and some everyday strategies for preserving and boosting it. It also sets out the benefits, including economic benefits, of doing so.

Following the formation of the Coalition Government in May 2010, it became clear that *New Horizons* was not to be fully implemented and the Government announced that it would introduce a replacement mental health strategy that built upon the strengths of *New Horizons*, but placed a clearer focus on outcomes and greater clarity on delivery. *No Health without Mental Health*<sup>20</sup> was published in 2011 and replaces *New Horizons* as the main policy driver for mental health services in England.

The strategy is supported by a series of documents including the economic case for improving efficiency and quality in mental health, an outcomes paper, a four year action plan of action to improve access to talking therapies and an impact assessment. The overall aims of the strategy are to improve outcomes for people with mental health problems, and to improve the mental health and wellbeing of the population and keep people well.

The aims and principles are underpinned by six high-level mental health objectives:

- More people will have good mental health.
- More people with mental health problems will recover.
- More people with mental health problems will enjoy good physical health.
- More people will have positive experiences of care and support.
- Fewer people will suffer avoidable harm.
- Fewer people will experience stigma and discrimination.

Each objective is supported by a series of actions. *No Health without Mental Health* is described as a cross-cutting and cross-Government strategy linked to the NHS, public health and local authority outcomes frameworks. The Government's cabinet sub-committee on public health will oversee the implementation of the strategy.

Local government will play a central role in ensuring that local partners and partnership arrangements can deliver the shared mental health objectives via the local health and wellbeing boards. The new enhanced role played by local government in delivering public health recognises that mental health is intrinsic to positive health and wellbeing.

#### 2.2 Health service commissioning

In 2007, the Department of Health published its *Commissioning Framework for Health and Wellbeing*, which advocated the provision of services to meet needs, not only the treatment of presenting conditions but also to enable people to maintain healthy and independent lives.

The report said that commissioning had been too focused on volume and price, rather than quality and outcomes, with much service provision being service-led rather than needs-led, and provided at the convenience of providers rather than patients. The needs of patients are now accepted as being central to the NHS.

The framework identified eight steps to effective commissioning which include:

- Putting people at the centre.
- Understanding the needs of populations and individuals.
- Sharing and using information more effectively.
- Assuring high quality providers.
- Recognising the interdependence between work, health and wellbeing.

<sup>&</sup>lt;sup>20</sup> No health without mental health. Department of Health 2011

- Developing incentives for commissioning for health and wellbeing.
- Making it happen local accountability.
- Making it happen capability and leadership.

The framework aspired to achieve:

- A shift towards services that are personal, sensitive to individual need and that maintain independence and dignity.
- A strategic reorientation towards promoting health and wellbeing, investing now to reduce future ill-health costs.
- A stronger focus on commissioning the services and interventions that will achieve better health, across health and local government, with everyone working together to promote inclusion and tackle health inequalities.

The *Crisis Care Concordat* published in February 2014 was created in partnership across health and social care, police and justice, local government and housing. It aims to improve emergency support for people in mental health crisis and drive up standards of care for people experiencing crisis such as suicidal thoughts or significant anxiety. The Concordat aims to help cut the numbers of people detained inappropriately in police cells and address variation in standards across the country.

The Crisis Care Concordat challenges local areas to review their services and make sure that:

- Health-based places of safety and beds are available 24/7 in case someone experiences a mental health crisis.
- Police custody should not be used because mental health services are not available and police vehicles should also not be used to transfer patients. The number of occasions police cells are used as a place of safety for people in mental health crisis should be halved compared to 2011/12.
- Timescales are put in place so police responding to mental health crisis know how long they have to wait for a response from health and social care workers. This will make sure patients get suitable care as soon as possible.
- People in crisis should expect that services will share essential 'need to know' information about them so they can receive the best care possible. This may include any history of physical violence, self-harm or drink or drug history.
- Figures suggest some minority ethnic groups are detained more frequently under the Mental Health Act. Where this is the case, it must be addressed by local services working with local communities so that the standards set out in the Concordat are met.
- A 24-hour helpline should be available for people with mental health problems and the crisis resolution team should be accessible 24 hours a day, 7 days a week.

Examples of good practice highlighted in the concordat included:

- A single point of access into crisis care, with well-trained triage and tele-health workers who are supported by continuously available services.
- Home treatment teams, so that when an individual is experiencing crisis, attendance at accident & emergency services and admissions can be avoided.

- High quality liaison mental health services for individuals who go to accident & emergency departments.
- Liaison and diversion services and street triage, able to refer individuals with existing mental health and substance misuse problems to appropriate services.

### 2.3 Carers

Carers play a vital role in supporting the health needs of adults and older people with mental health disorders. The health needs of carers are outside of the scope of this report, but will be the subject of another forthcoming joint strategic needs assessment, which will recognise that carers can be seriously affected by mental health problems in the people for whom they care. Supporting carers is vital if these patients are to be able to continue to live in the community, which has important implications for the NHS and other statutory organisations.

### 2.4 Report structure

This report starts by describing the population of Cambridgeshire, with particular emphasis on the adult population and the factors which contribute to mental health problems in that age group. These are factors which are known to be risk factors for reduced mental wellbeing and therefore mental illness in some.

It goes on to estimate how many people in Cambridgeshire have the disorders covered by this report, both now and in the future. The report then describes the present pattern of services available in Cambridgeshire for people with these disorders, and report's findings from research about the interventions which, if used early in the course of illness, may reduce its severity. The report then summarises the results of engagement with service users, carers and providers, before setting out some conclusions and recommendations.

Needs assessment depends on understanding the present pattern of service use and how resources are directed. For NHS mental health services, the most appropriate source for these is the mental health minimum dataset, which contains details of each episode of care provided through the NHS, anonymised to protect patient confidentiality. No access to this dataset was possible within the four-month timescale of this project. This report therefore contains no information on the volume or cost of mental health services for adults apart from some limited activity information from key performance indicators provided by Cambridgeshire CCG.

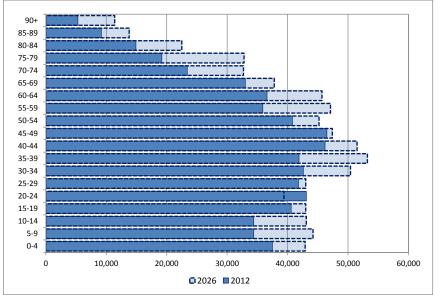
### 3. Demography and prevalence

This section sets out information about the current and future population of Cambridgeshire, a key determinant of future health needs. It then describes features of the population which contribute to the occurrence of mental health problems, and estimates the current and future numbers of people with the mental health problems of interest in this report.

### 3.1 Demography

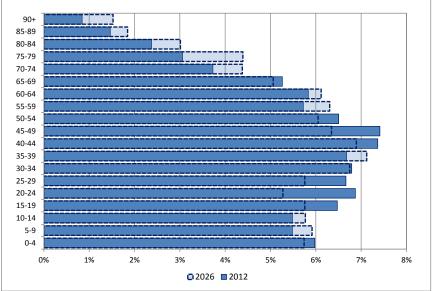
We used population projections from Cambridgeshire County Council, based on 2011 data, to construct population projections for age-bands for each year from 2011 to 2026. Detailed results for each district are in appendix 1.

Figure 1: Population projections by age-band, Cambridgeshire, 2012 and 2026: numbers of people



Source: Cambridgeshire County Council

Figure 2: Population projections by age-band, Cambridgeshire, 2012 and 2026: proportion of the population



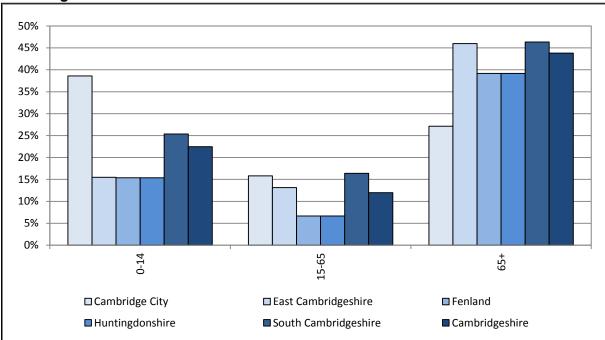
Source: Cambridgeshire County Council

Figure 3 (below) shows the expected changes in the population of Cambridgeshire and its districts between 2012 and 2026. Most adult categories show increases, though these vary between districts and age groups with increases in the adult population concentrated in Cambridge City.

Age Group	Cambridge City	East Cambridgeshire	Fenland	Fenland Huntingdonshire		Cambridgeshire	
0-4	25%	4%	8%	12%	20%	14%	
5-9	51%	18%	24%	24%	28%	28%	
10-14	44%	27%	15%	19%	28%	25%	
15-19	-5%	24%	-4%	6%	17%	6%	
20-24	0%	-8%	-14%	-24%	-6%	-9%	
25-29	-4%	2%	-2%	1%	20%	3%	
30-34	20%	9%	15%	19%	23%	18%	
35-39	20%	22%	27%	30%	33%	27%	
40-44	53%	5%	3%	-1%	7%	11%	
45-49	40%	2%	-11%	-9%	0%	2%	
50-54	3 <mark>0%</mark>	14%	3%	2%	13%	11%	
55-59	31%	36%	26%	30%	33%	31%	
60-64	31%	27%	23%	23%	24%	25%	
65-69	15%	17%	15%	15%	12%	15%	
70-74	32%	42%	38%	41%	42%	40%	
75-79	36%	75%	5 <mark>5%</mark>	92%	79%	71%	
80-84	22%	45%	33%	78%	59%	<mark>51</mark> %	
85-89	12%	46%	47%	77%	57%	50%	
90+	73%	143%	144%	115%	115%	115%	
Grand Total	20%	19%	15%	17%	23%	19%	

### Figure 3: Population changes from 2012 to 2026, by age-band and district, Cambridgeshire

Source: Cambridgeshire County Council



## Figure 4: Population changes from 2012 to 2026, by age category and district, Cambridgeshire

Source: Cambridgeshire County Council

## Figure 5: Population changes from 2012 to 2026, by age category and district, Cambridgeshire

Age Group	Cambridge City	East Cambridgeshire	Fenland	Huntingdonshire	South Cambridgeshire	Cambridgeshire
0-14	39%	15%	15%	18%	25%	22%
15-64	16%	13%	7%	7%	16%	12%
65+	27%	46%	39%	52%	46%	44%
Grand Total	20%	19%	15%	17%	23%	19%

Source: Cambridgeshire County Council

### 3.2 Factors affecting the risk of mental illness

A variety of factors are associated with the risk of mental illness. These associations may not be causal and in some cases are not strong, but they are reported here to provide as much information as possible about the context for adult mental illness and the disorders of interest.

### Deprivation

The relationship between high levels of deprivation and high rates of mental ill-health is well established<sup>21</sup>. Studies have found an association between mental health and socioeconomic status, showing higher rates of psychiatric admissions and suicides in areas of high deprivation and unemployment<sup>22,23,24,25</sup>. There may also be an association between

<sup>&</sup>lt;sup>21</sup> Payne, S. (2000) Poverty, social exclusion and mental health: findings from the 1999 PSE survey. Working Paper no. 15. Poverty and Social Exclusion Survey of Britain: Townsend Centre for International Poverty Research. Bristol: University of Bristol.

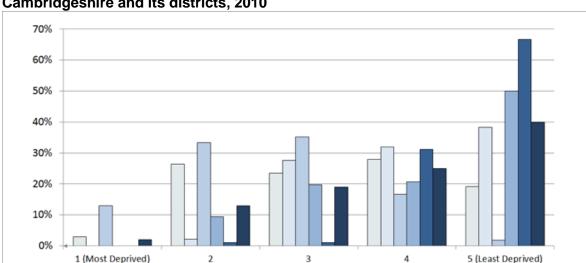
Kammerling, M. and O'Connor, S. (1993) Unemployment rate as predictor of rate of psychiatric admission.
 British Medical Journal, 307, 1536 – 9

deprivation and dual diagnosis. Regardless of age or gender, there is an increased risk of mental ill-health for the poor when compared to the better-off21.

The Index of Multiple Deprivation (IMD) 2010 produced by Department for Communities and Local Government (DCLG) combines a number of indicators, chosen to cover a range of economic, social and housing issues, into a single deprivation score for each small area in England. The domains of IMD are:

- Income deprivation.
- Employment deprivation.
- Health deprivation and disability.
- Education, skills and training deprivation.
- Barriers to housing and services.
- Living environment deprivation.
- Crime.

Figure 6 shows the pattern of deprivation in Cambridgeshire and districts within the County. The height of each column shows the proportion of neighbourhoods which fall into each quintile (or fifth) of deprivation for England. It shows that few of the neighbourhoods in the County are in the most deprived quintile for England, and 40% are in the most affluent. South Cambridgeshire is the most affluent of Cambridgeshire's districts, and Fenland the most deprived.



□ Cambridge City □ East Cambridgeshire □ Fenland □ Huntingdonshire ■ South Cambridgeshire ■ Cambridgeshire

Figure 6: Proportion of lower super-output areas in each deprivation quintile for Cambridgeshire and its districts, 2010

Source: Office for National Statistics

<sup>&</sup>lt;sup>23</sup> Gunnell, D., Peters, T., Kammerling, M. and Brooks, J. (1995) The relationship between parasuicide, suicide, psychiatric admissions and socioeconomic deprivation. British Medical Journal, 311, 226 – 230.

<sup>&</sup>lt;sup>24</sup> Boardman, A.P., Hodgson, R.E., Lewis, M. and Allen, K. (1997) Social indicators and the prediction of psychiatric admission in different diagnostic groups. British Journal of Psychiatry, 171, 457 – 462.

 <sup>&</sup>lt;sup>25</sup> Croudace, T.J., Kayne, R., Jones, P.B. and Harrison, G.L. (2000) Non-linear relationship between an index of social deprivation psychiatric admission prevalence and the incidence of psychosis. Psychological Medicine, 30, 177 – 185.

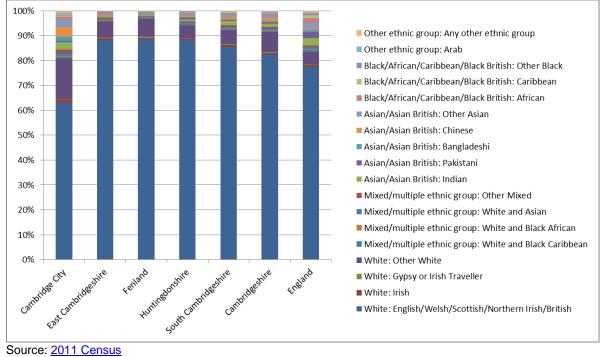
### Ethnicity

The relationship between ethnicity and mental health is complex with well-documented inequalities at a national and local level.

National survey findings estimate there to be little difference in prevalence rates of common mental health problems between minority ethnic groups and the white population. Specific group differences showed that Irish men and Pakistani women had higher rates, while Bangladeshi women had lower rates.

In relation to severe mental health problems, significant variations were found. Black Caribbean people showed a two-fold excess. Pakistani people had a 60% higher and Bangladeshi people a 25% lower rate, both with no apparent gender difference. Irish people showed similar rates to the rest of the white population, though with a greater concentration in younger people<sup>26</sup>. In addition, rates of suicide and self-harm are higher in young Asian women<sup>27</sup>.

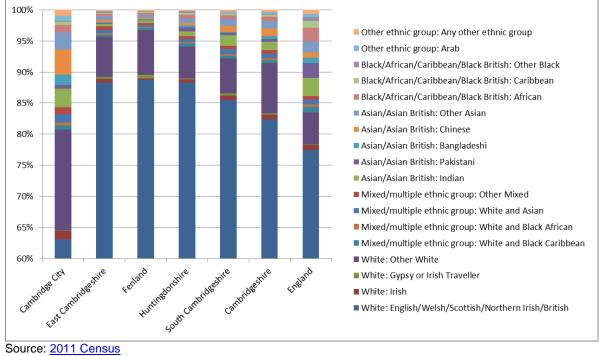
Figure 7 shows the ethnic composition of the population of Cambridgeshire, districts within the County and England, and Figure 8 shows the same data with a reduced axis so that ethnic minorities are more clearly displayed. Cambridge has a much more ethnically diverse population than other parts of the County, and has a lower white population than England as a whole, while Cambridgeshire and the other districts show much less diversity than England. White Eastern European migrants are not identified as a separate ethnic category in these figures.



### Figure 7: Ethnicity, under 65s showing category details for Cambridgeshire, districts in Cambridgeshire and England, 2011

<sup>&</sup>lt;sup>26</sup> Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC) Quantitative Report, ONS, 2002

<sup>&</sup>lt;sup>27</sup> Mental health NSF, DH,1999



## Figure 8: Ethnicity, under 65s showing category details for Cambridgeshire, districts in Cambridgeshire and England, 2011 with reduced axis

#### Social support, long term conditions, unemployment and housing

A clear relationship between social support and the risk of mortality and morbidity has been identified<sup>28</sup>. Social support is a feature of a person's social network and was measured in the social capital module of the 2000 General Household Survey<sup>29</sup>.

Social networks are quantified as the number, frequency and density of contacts with other people. There is a strong relationship between social networks and mental health: those with few social contacts are at increased risk of mental health problems<sup>30</sup>.

Social networks can prevent problems arising from stress and research suggests that they can help women recover from depression<sup>31</sup>. Young people, women and some ethnic groups have better social networks, but some, for example Black ethnic minority groups, have poorer networks.

Neighbourliness relates to the percentage of adults speaking to their neighbours, the number of neighbours known and how many are trusted, as well as whether people have received favours from their neighbours in the previous week. It is considered an important aspect of social capital and provides protection from mental health problems<sup>32</sup>.

<sup>&</sup>lt;sup>28</sup> Indications of Public Health in the English Regions 7: Mental Health. APHO, 2007 <u>http://www.apho.org.uk/resource/item.aspx?RID=39303</u>

<sup>&</sup>lt;sup>29</sup> Coulthard, M., Walker, A. and Morgan, A. People's perceptions of their neighbourhood and community involvement: Results from the Social Capital Module of the General Household Survey 2000. London: TSO.2002

 <sup>&</sup>lt;sup>30</sup> Stewart-Brown, S. Interpersonal relationships and the origins of mental health. Journal of Public Mental Health2002; 4(1) 24-29
 <sup>31</sup> Device T. S. NegOerthe, D. Stert, F. Mador T. and Patter, J. Conden assistered as a single second second

<sup>&</sup>lt;sup>31</sup> Brugha, T.S., Bebbington, T.E., MacCarthy, B., Sturt, E., Wykes, T. and Potter, J. Gender, social support and recovery from depressive disorders: A prospective clinical study. Psychological Medicine 1990; 20 (1): 147 – 156

<sup>&</sup>lt;sup>32</sup> Social Exclusion Unit. Social Exclusion and Mental Health. London: Office of the Deputy Prime Minister.2004

The proportion of adult social care users who have as much social contact as they would like is 44.7% in Cambridgeshire, similar to the 43.2% reported for England as a whole. This information is not available at district level.

Figure 9 shows the proportion of people whose daily activities are limited by long-term illness or disability. A long-term health problem or disability that limits a person's day-to-day activities, and has lasted, or is expected to last, at least a year. Overall, these problems are less common in Cambridgeshire than in England, but again, Fenland appears more severely affected than other parts of the County, and Cambridge less severely affected.

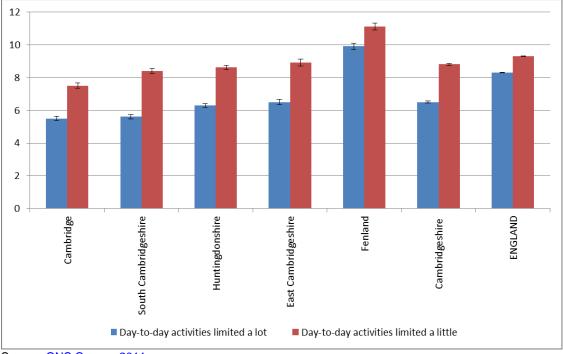


Figure 9: Proportion of the population with daily activities limited by a long-term condition, Cambridgeshire and England, 2011

Source: ONS Census 2011

The importance of work in maintaining good mental health has been clear. The corollary of this is that unemployment is associated with poor mental health. The OPCS Psychiatric Morbidity Survey found that unemployed respondents were the group most likely to suffer high levels of all psychiatric disorders<sup>33</sup>. This is a complex issue, because people may be less likely to be in paid employment due to mental illness, while unemployment may lead to deterioration in mental health. Both factors play a role, but the latter is probably predominant<sup>34</sup>.

<sup>&</sup>lt;sup>33</sup> Meltzer H et al. The prevalence of psychiatric morbidity among adults living in private households, in OPCS Surveys of Psychiatric Morbidity in Great Britain 1995. London: HMSO

<sup>&</sup>lt;sup>34</sup> Wilson, S. & Walker, G. Unemployment and health. A review. Public Health 1993; 107: 153–162

Unemployment rates in Cambridgeshire are highest in Fenland and lowest in East Cambridgeshire and South Cambridgeshire (Figure 10).

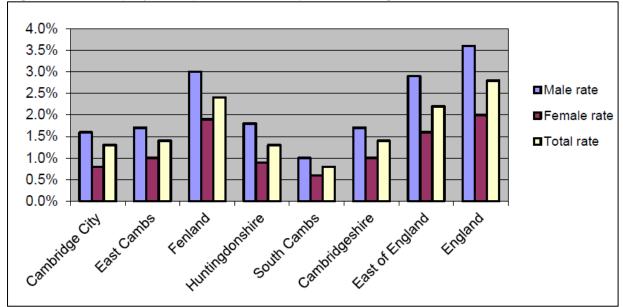
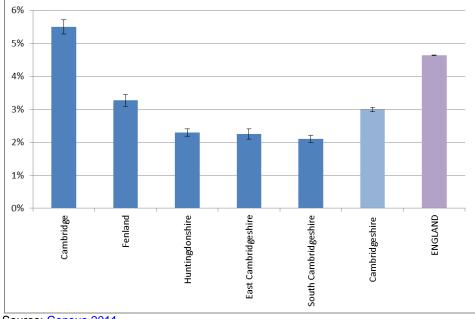


Figure 10: Unemployment (claimant count) in Cambridgeshire, March 2014

Source: Office for National Statistics

Safe and secure housing is important to mental health. Figure 11 shows the proportion of households without a bedroom in their dwelling. All parts of the county are lower than England except Cambridge; this may reflect the accommodation arrangements of single students in the City.

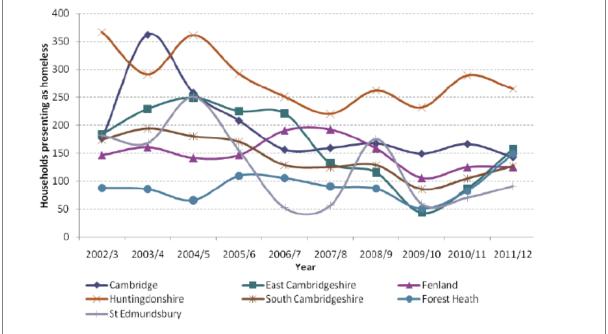
Figure 11: proportion of households lacking at least one bedroom, Cambridgeshire and England, 2011



Source: Census 2011

Homelessness in Cambridgeshire is most common in Huntingdonshire and least common in Cambridge and South Cambridgeshire<sup>35</sup>. Figure 12 shows the number of households presenting to local authorities for homelessness decisions between 2002/3 and 2011/12 in each district.

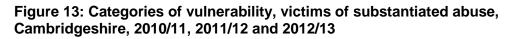


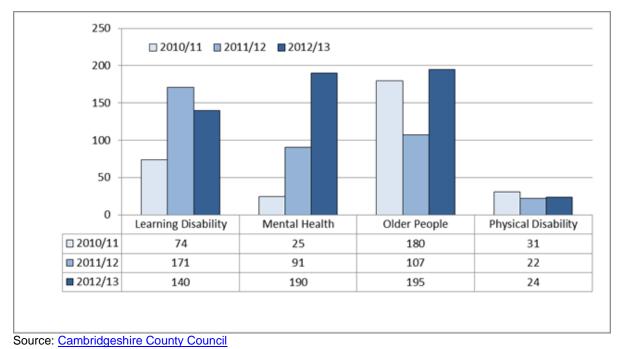


Source: <u>Chapter 9. Homelessness. Cambridge sub-region Strategic Housing Market Assessment</u> Note: Forest Heath and St. Edmundsbury are both districts within Suffolk, bordering East and South Cambridgeshire. Data is provided in clusters. As such it was not possible to exclude these districts from the above graph.

Adult safeguarding referrals give an indication of the vulnerability of some of those who have mental health problems. Figure 13 shows the categories of people referred to the Council's safeguarding team in whom abuse was substantiated. Mental health, learning disability and older people account for the majority of cases.

<sup>&</sup>lt;sup>35</sup> www.cambridgeshireinsight.org.uk/housing/tackling-homelessness





### 3.3 Mental health and life expectancy/mortality

Mental health and physical health are intricately related. The national mental health strategy, *No Health without Mental Health* states that having a mental health problem increases the risk of physical ill health.

In relation to common mental health disorders:

- Depression increases mortality by 50% and has been associated with a four-fold increase in the risk of heart disease, even when other factors are controlled for<sup>36</sup>.
- Untreated depression and anxiety disorders are associated with increased healthcare usage, not only ongoing consultations and treatment in relation to the specific mental health condition, but also increased healthcare usage more generally<sup>37</sup>.
- Co-morbid mental health problems have a significant impact on the costs related to the management of long-term conditions. For example, the total cost to the health service of each person with diabetes and co-morbid depression is 4.5 times greater than the cost for a person with diabetes alone<sup>38</sup>.

<sup>&</sup>lt;sup>36</sup> Mykletun A, Bjerkeset O, Overland S et al. Levels of anxiety and depression as predictors of mortality: the HUNT study. British Journal of Psychiatry 2009; 195: 118-125

<sup>&</sup>lt;sup>37</sup> Layard R et al. Cost benefit analysis of psychological therapy. Centre for Economic Performance. CEP Discussion paper No 829, October 2007

<sup>&</sup>lt;sup>38</sup> Egede LE, Zheng D, Simpson K. Comorbid depression is associated with increased healthcare use and expenditures in individuals with diabetes". Diabetes Care 2002, vol 25, no 3, pp 464–70

In May 2013, a BMJ editorial stated that "the gap between life expectancy in patients with a mental illness and the general population has widened since 1985 and efforts to reduce this gap should focus on improving physical health"<sup>39</sup>.

The higher death rate associated with mental illness has been extensively documented, but most of the attention has focused on the elevated risk of suicide, whereas most of the risk can be attributed to physical illness such as cardiovascular and respiratory diseases and cancer (80% of deaths). Of the few studies of life expectancy in people with mental illness, some have reported a gap of 14-20 years for males and 6-15 years for females. It has been estimated that people with severe mental illness (usually conditions with psychosis, such as schizophrenia and bipolar disorder) die 10 years younger than other people because of poor physical health.

An Australian study showed that among psychiatric patients, those with alcohol or drug disorders had the lowest life expectancy in 1985 which exceeded 20 years compared with the general population.

Although suicides represented a large proportion of excess deaths for patients with severe mental illness, physical conditions represent the majority of excess deaths. Cardiovascular disease was the main cause particularly for patients with schizophrenia (32% males, 46% females), other psychoses (33% males, 41% females) and neurotic disorders (38% males, 38% females).

The widest gap in life expectancy was observed in people with alcohol and drug disorders and this was maintained through the period of the study. Substance abuse is a wellestablished risk for cardiovascular disease and many cancers which makes these findings less surprising.

The Australian study noted that there were significant advances in reducing death rates due to common physical conditions, but highlighted that people with mental illness have not benefited to the same extent as the general population.

The editorial focused on the impact of mental illness on life expectancy and highlighted that while strategies aimed at the prevention of suicides were an important component, "80% of excess deaths are associated with physical conditions" and that "multi-pronged approaches will be required to address these inequalities". They also stress that treating both physical health problems and risk factors "would result in improvements to both physical and mental health".

In a large UK study<sup>40</sup> published in 2012, it was found that life expectancy at birth was 63.3 years for women and 59.1 years for men with PD—18.7 years and 17.7 years shorter than females and males respectively in the general population in England and Wales. People with PD using mental health services have a substantially reduced life expectancy, highlighting the significant public health burden of the disorder.

<sup>&</sup>lt;sup>39</sup> Lawrence D, Hancock K, Kisely S The gap in life expectancy from preventable physical illness in psychiatric patients in Western Australia: retrospective analysis of population based registers. *BMJ* 2013;346:f2539

<sup>&</sup>lt;sup>40</sup> Marcella Lei-Yee Fok, Richard D. Hayes, Chin-Kuo Chang, Robert Stewart, Felicity J. Callard, Paul Moran Life expectancy at birth and all-cause mortality among people with personality disorder Journal of Psychosomatic Research Volume 73, Issue 2, August 2012, Pages 104–107 http://dx.doi.org/10.1016/j.jpsychores.2012.05.001

No comparable Cambridgeshire figures are available for the conditions of interest in this report, but physical health and mental health are inseparable and demand a holistic approach to the care of all patients with mental health problems.

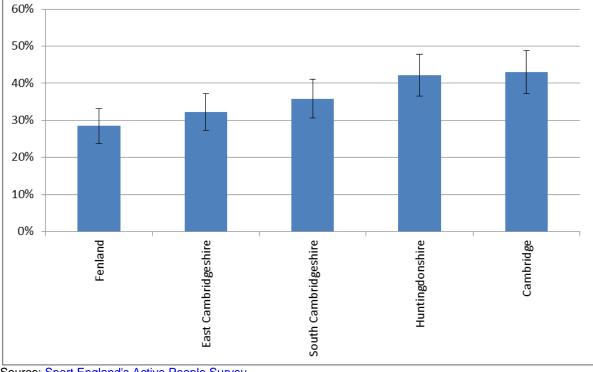
### 3.4 Lifestyle factors

Physical activity is known to be associated with less depression and anxiety, better sleep, better concentration and possibly a reduced likelihood of problems with memory and dementia<sup>41</sup>. Structured group physical activity programmes are one of the treatments options recommended by NICE for people with mild to moderate common mental health disorders<sup>42</sup>.

Figures 14 and 15 reflect data collected as part of the Sport England Active People Survey 2012-2013. Datasets for 2,491 respondents were collected from Cambridgeshire residents with between 490 and 507 responses from each of the five Cambridgeshire Districts<sup>43</sup>.

Figure 14 shows the proportion of adults who report taking an adequate amount of physical activity in the previous month. In all parts of Cambridgeshire, fewer than half achieve these levels, but physical activity levels are reported as highest in Cambridge and Huntingdonshire and lowest in Fenland.





Source: Sport England's Active People Survey

<sup>&</sup>lt;sup>41</sup> Royal College of Psychiatrists. Physical activity and mental health. November 2012. Available from <u>http://www.rcpsych.ac.uk/mentalhealthinfoforall/treatments/physicalactivity.aspx</u> (Accessed July 2013)

<sup>&</sup>lt;sup>42</sup> National Institute for Health and Clinical Excellence. Common mental health disorders: Identification and pathways to care. Clinical Guidelines 123, May 2011

<sup>&</sup>lt;sup>43</sup> <u>http://www.sportengland.org/media/312344/Active-People-Survey-6 Technical-Report final.pdf</u> (accessed April 2014)

These results are corroborated by Figure 15, showing days in which adults took part in physical activity.

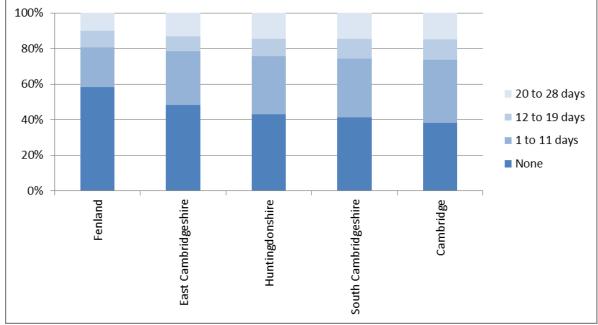


Figure 15: Number of days of participation in physical activity in the last 28 days, Cambridgeshire, 2011/13

Source: Sport England's Active People Survey

People with mental health problems may be less able to prevent or deal with overweight and obesity. The health consequences of obesity include diabetes, heart disease, stroke, cancer, respiratory disease, reproductive disorders, osteoarthritis, stigma and mental health issues and, in the UK, some 30,000 deaths per year.

Prevalence of obesity has increased in the past 25 years in every age-group, social class, ethnicity and gender. In 1986, 8% of men and 12% of women were obese. Today it is estimated that 24% of men and 26% of women are obese.

People at greater risk of being obese are people in lower socioeconomic groups, socially disadvantaged groups and women. In women, the mean body mass index (BMI) is markedly higher in Black Caribbeans and Black Africans than in the general population, and markedly lower in Chinese. In men, the mean BMI of Chinese and Bangladeshi is significantly lower than that of the general population. The average BMI is markedly higher amongst people of black Caribbean and black African ethnicity. Some mental health diagnoses are more common people of this ethnic group, though not specifically the diagnoses of interest in this report.

Severely obese individuals (those with a BMI over 40) are likely to die on average 11 years earlier than those with a healthy weight.

Figure 16 shows the prevalence of overweight and obesity in adults in Cambridgeshire and England. The County as a whole has a prevalence similar to that of England, but obesity is significantly lower in Cambridge (perhaps because it has a younger population) and higher in Huntingdonshire and Fenland.

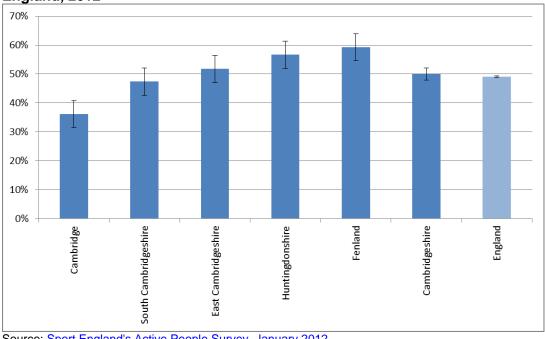


Figure 16: Prevalence of overweight and obesity<sup>44</sup> in adults, Cambridgeshire and England, 2012

Source: Sport England's Active People Survey, January 2012

Figure 17 shows the prevalence of smoking in adults in Cambridgeshire and England. People with mental health problems are more likely to smoke, but often experience better quality of life once they quit<sup>45</sup>.

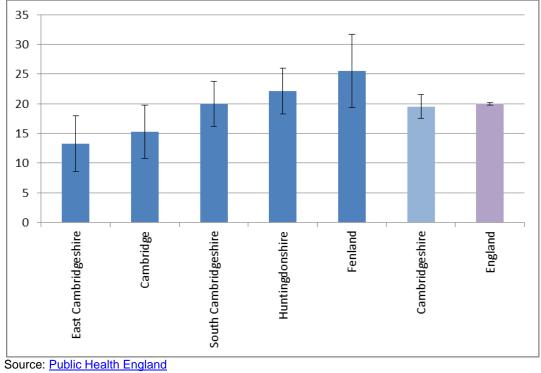


Figure 17: Smoking prevalence among adults, Cambridgeshire and England, 2012

<sup>44</sup> Overweight or obese people have a body mass index of at least 25 kg/m<sup>2</sup>.

<sup>45</sup> Taylor G, McNeill A, Girling A, Farley A, Lindson-Hawley N, Aveyard P. Change in mental health after smoking cessation: systematic review and meta-analysis BMJ 2014;348:g1151

Figure 18 shows the rate of people of working age claiming incapacity benefit or severe disablement allowance. Some of the claimants will have mental health problems. There has been a steep recent fall in claimants, which may reflect government policy initiatives.

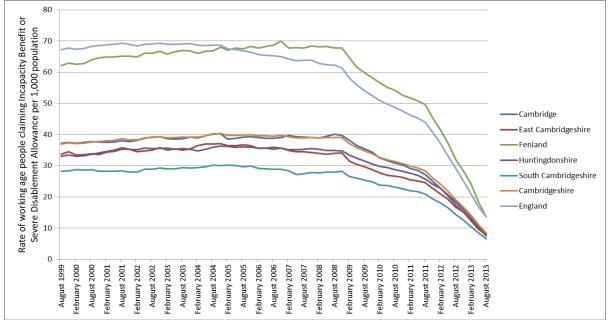


Figure 18: People of working age claiming incapacity benefit or severe disablement allowance per 1,000 population, Cambridgeshire, 1999 to 2013

Source: NOMIS

Figure 19 show the proportion of people receiving social security benefits who have mental health and behavioural disorders. Overall, the proportion is similar to England, but in Cambridge it is somewhat higher.

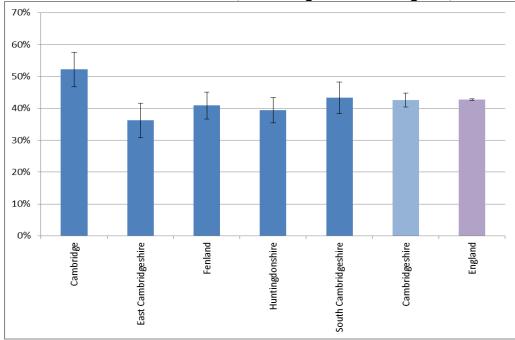


Figure 19: Proportion of incapacity benefit and severe disablement claimants with mental and behavioural disorders, Cambridgeshire and England, 2013

Source: NOMIS

### 3.5 Current and future prevalence of mental illness

Prevalence is a measure of the proportion of a population that has a condition at a specific point in time.

We do not know the true number of people with the conditions of interest in Cambridgeshire because not all of those people living with the condition have been diagnosed with the condition. This means that we have to use ways to estimate the number of people with these and other conditions in the County.

We obtained projections of the future population of Cambridgeshire local authorities from Cambridgeshire County Council, and estimates of the prevalence of mental illnesses from Projecting Adult Needs and Service Information (PANSI). These are resources provided by the Institute of Public Care at Oxford Brookes University. We applied the prevalence estimates to the population projections to estimate the number of people with mental illness expected in the years 2012, 2014, 2016, 2018 and 2020. The estimates are based on an assumption that there is no change in age-specific rates over this period.

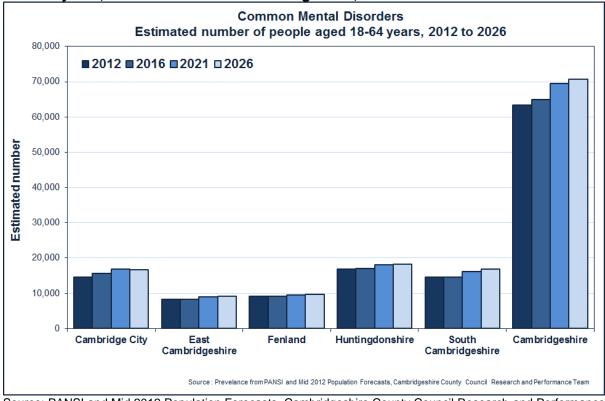
PANSI uses prevalence estimates from authoritative sources such as the National Psychiatric Morbidity Survey. The Adult Psychiatric Morbidity Survey 2007 was undertaken by NatCen, with around 7,400 people aged 16 years and over in private households being interviewed. The first phase interviews included structured assessments using diagnostic criteria and screening instruments for a range of mental disorders, as well as questions on topics such as general health, service use, risk factors and demographics. Questions were asked around depression, depressive ideas, worry, anxiety, panic, compulsions, obsessions, fatigue, somatic symptoms, phobias, sleep problems, irritability, worry about physical health, concentration and forgetfulness. The second phase interviews were carried out by clinically trained research interviewers. A sub-sample of phase one respondents was invited to take part in the second phase interview. The Survey is undertaken every seven years, with the 2014 survey currently underway. It is anticipated that the results will be published by the Health and Social Care Information Centre by late 2016.

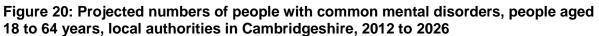
#### **Common Mental Health Disorders**

Figure 20 shows the number of people of working age expected to have a "common mental health problem". These are defined as "mental conditions that cause marked emotional distress and interfere with daily function, but do not usually affect insight or cognition. They comprise different types of depression and anxiety, and include obsessive compulsive disorder<sup>46</sup>." Twenty per cent of women and twelve per cent of men surveyed met the diagnostic criteria for at least one common mental health condition.

Table 21 shows increases in line with the rising local population.

<sup>&</sup>lt;sup>46</sup> Health and Social Care Information Centre. Adult psychiatric morbidity in England, 2007: Results of a household survey. 2009





Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

Table 21: Changes in projected numbers of people aged 18 to 64 with common mental
disorders compared with 2012, local authorities in Cambridgeshire, 2012 to 2026

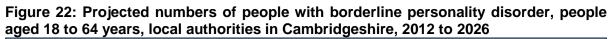
Local Authority	Estimated number				Ch	% change 2012 to		
	2012	2016	2021	2026	2012 to 2016	2016 to 2021	2021 to 2026	2012 10
Cambridge City	14,500	15,700	16,900	16,700	1,200	1,200	-200	15.2%
East Cambridgeshire	8,300	8,300	8,900	9,200	0	600	300	10.8%
Fenland	9,100	9,200	9,500	9,700	100	300	200	6.6%
Huntingdonshire	16,900	17,000	18,000	18,200	100	1,000	200	7.7%
South Cambridgeshire	14,500	14,600	16,100	16,800	100	1,500	700	15.9%
Cambridgeshire	63,300	64,900	69,500	70,700	1,600	4,600	1,200	11.7%

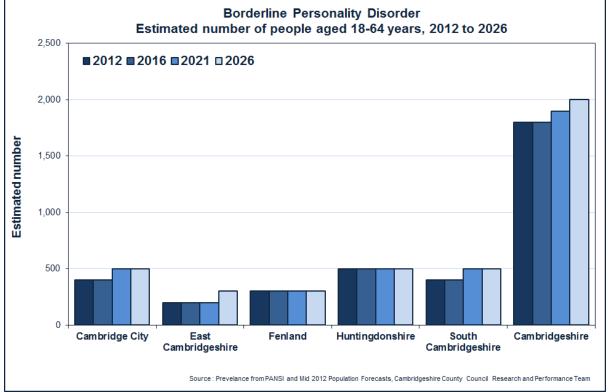
Note : Total may not agree due to rounding

Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

### **Borderline Personality Disorders**

Figure 22 shows the number of people of working age expected to have borderline personality disorder. The National Psychiatric Morbidity Survey found that 0.3% of men and 0.6% women with borderline personality disorder. Again, the changes in prevalence reflect population growth, a pattern repeated in the graphs below. The number is expected to rise from 1,800 in 2012 to 2,000 in 2026, a rise of 11% in line with population. This is the proportionate increase seen in all the prevalence projections below.





Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

### Table 23: Changes in projected numbers of people with borderline personality disorder compared with 2012, local authorities in Cambridgeshire, 2012 to 2026

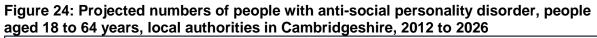
Local Authority	Estimated number				Ch	% change 2012 to		
	2012	2016	2021	2026	2012 to 2016	2016 to 2021	2021 to 2026	201210
Cambridge City	400	400	500	500	0	100	0	25.0%
East Cambridgeshire	200	200	200	300	0	0	100	50.0%
Fenland	300	300	300	300	0	0	0	0.0%
Huntingdonshire	500	500	500	500	0	0	0	0.0%
South Cambridgeshire	400	400	500	500	0	100	0	25.0%
Cambridgeshire	1,800	1,800	1,900	2,000	0	100	100	11.1%

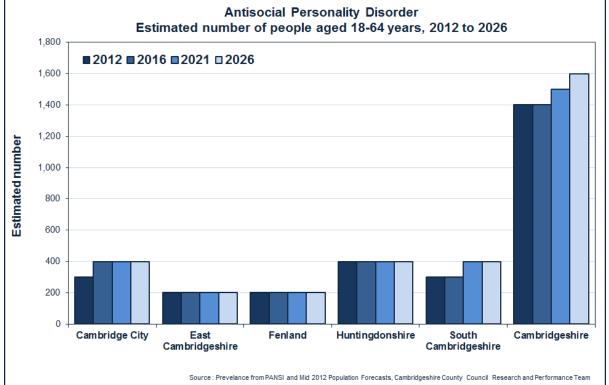
Note: Total may not agree due to rounding

Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

### **Anti-social Personality Disorder**

Figure 24 shows the number of people of working age expected to have anti-social personality disorder. The National Psychiatric Morbidity Survey found 0.6% of men and 0.1% of women with anti-social personality disorder. These are expected to rise from 1,400 to 1,600.





Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

disorder compared with 2012, local authorities in Cambridgeshire, 2012 to 2026									
Local Authority	Estimated number				Ch	% change 2012 to			
	2012	2016	2021	2026	2012 to 2016	2016 to 2021	2021 to 2026	2012 10	
Cambridge City	300	400	400	400	100	0	0	33.3%	
East Cambridgeshire	200	200	200	200	0	0	0	0.0%	
Fenland	200	200	200	200	0	0	0	0.0%	
Huntingdonshire	400	400	400	400	0	0	0	0.0%	

400

1,600

0

0

100

100

0

100

## Table 25: Changes in projected numbers of people with anti-social personality

Total may not agree due to rounding Note :

300

1,400

300

1,400

South Cambridgeshire

Cambridgeshire

Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

400

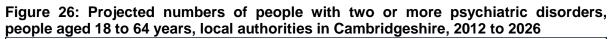
1,500

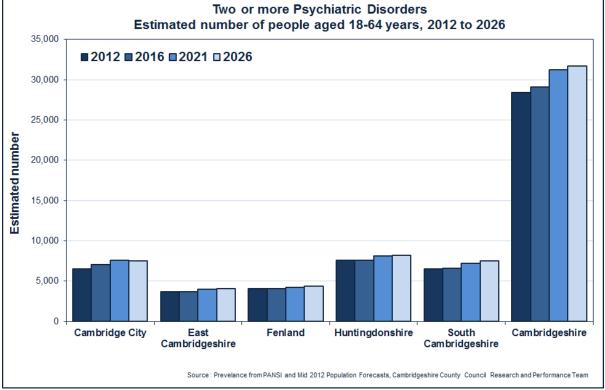
33.3%

14.3%

### **Psychiatric Disorders**

Figure 26 shows the number of people of working age expected to have two or more psychiatric disorders. The National Psychiatric Morbidity Survey found 6.9% of men and 7.5% of women with two or more psychiatric disorders. In some cases these will include the conditions of interest in this report, though we cannot determine how common this is. Psychiatric co-morbidity - or meeting the diagnostic criteria for two or more psychiatric disorders - is known to be associated with increased severity of symptoms, longer duration, greater functional disability and increased use of health services. Disorders included the most common mental disorders (namely anxiety and depressive disorders) as well as: psychotic disorder; antisocial and borderline personality disorders; eating disorder; posttraumatic stress disorder; attention deficit hyperactivity disorder; alcohol and drug dependency; and problem behaviours such as problem gambling and suicide attempts.





Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

Table 27: Changes in projected numbers of people with two or more psychiatric
disorders compared with 2012, local authorities in Cambridgeshire, 2012 to 2026

Local Authority		Estimate	d number		Ch	% change			
	2012	2016	2021	2026	2012 to 2016	2016 to 2021	2021 to 2026	2012 to 2026	
Cambridge City	6,500	7,100	7,600	7,500	600	500	-100	15.4%	
East Cambridgeshire	3,700	3,700	4,000	4,100	0	300	100	10.8%	
Fenland	4,100	4,100	4,200	4,400	0	100	200	7.3%	
Huntingdonshire	7,600	7,600	8,100	8,200	0	500	100	7.9%	
South Cambridgeshire	6,500	6,600	7,200	7,500	100	600	300	15.4%	
Cambridgeshire	28,400	29,100	31,200	31,700	700	2,100	500	11.6%	

Note : Total may not agree due to rounding

Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

### **Dual Diagnosis**

The inter-relationships between substance misuse and mental health problems are complex, and as such projecting the prevalence of dual diagnosis is complicated. There are also likely to be variations between age specific prevalence figures and across different population groups<sup>47</sup>.

The 2002 Co-morbidity of Substance Misuse and Mental Illness Collaborative study (COSMIC), a department of health funded study, concluded that:

- 75% of users of drug services, and 85% of users of alcohol services were experiencing mental health problems and;
- 44% of mental health service users either reported drug use or were assessed to consume alcohol at hazardous or harmful levels<sup>48</sup>.

A 2002 study of the primary care sector in the London Borough of Bromley found that dual diagnosis was present in:

- 20% of community mental health clients;
- 43% of psychiatric in-patients and;
- 56% of people in secure services.

It has also been estimated that 75% of all prisoners have a dual diagnosis<sup>49</sup>.

Given the high numbers of people experiencing mental health problems who are also drug and alcohol dependent, the following sets out the projected numbers of alcohol and drug dependent individuals in Cambridgeshire to provide an indication of the likely scale of dual diagnosis within the County.

#### **Alcohol Dependence**

Figure 28 shows the number of people of working age expected to have alcohol dependence. The national psychiatric morbidity survey found 8.7% of men and 3.3% of women dependent on drugs. These estimates should be treated with caution, because the prevalence of excessive drinking is rising but the estimation method in PANSI assumes a constant age-specific prevalence.

<sup>&</sup>lt;sup>47</sup> Crome, I., Chambers, P., Frisher, M., Bloor, R., Roberts, D. (2009) The relationship between dual diagnosis: substance misue and dealing with mental health issues -

http://www.scie.org.uk/publications/briefings/files/briefing30.pdf
 <sup>48</sup> Weaver, T., Charles, V., Madden, P., Renton, A. (2002) A Study of the Prevalence and Management of Co-Morbidity amoungst Adult Substance Misuse and Mental Health Treatment Populations http://dmri.lshtm.ac.uk/docs/weaver\_es.pdf

 <sup>&</sup>lt;sup>49</sup> The Prison Reform Trust (2011) Bromley Breifings Prison Factfile http://www.prisonreformtrust.org.uk/Portals/0/Documents/Bromley%20Briefing%20December%202011.pdf

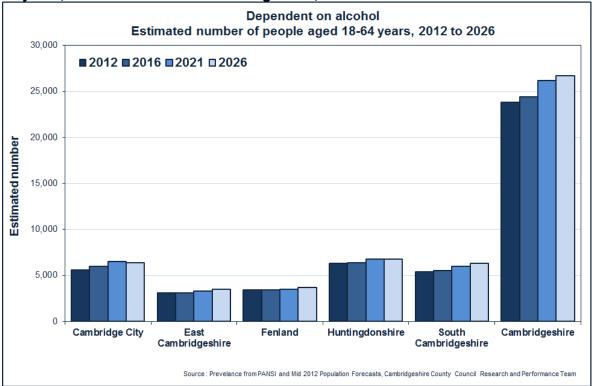


Figure 28: Projected numbers of people with alcohol dependence, people aged 18 to 64 years, local authorities in Cambridgeshire, 2012 to 2026

Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

Table 29: Changes in projected numbers of people with alcohol dependence
compared with 2012, local authorities in Cambridgeshire, 2012 to 2026

Local Authority	Estimated number			Ch	% change 2012 to			
	2012	2016	2021	2026	2012 to 2016	2016 to 2021	2021 to 2026	201210
Cambridge City	5,600	6,000	6,500	6,400	400	500	-100	14.3%
East Cambridgeshire	3,100	3,100	3,300	3,500	0	200	200	12.9%
Fenland	3,400	3,400	3,500	3,700	0	100	200	8.8%
Huntingdonshire	6,300	6,400	6,800	6,800	100	400	0	7.9%
South Cambridgeshire	5,400	5,500	6,000	6,300	100	500	300	16.7%
Cambridgeshire	23,800	24,400	26,200	26,700	600	1,800	500	12.2%

Note : Total may not agree due to rounding

Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

#### **Dependent on Illicit Drugs**

Figure 30 shows the number of people of working age expected to be dependent on illicit drugs. The National Psychiatric Morbidity Survey found 4.5% of men and 2.3% of women to be dependent on illicit drugs.

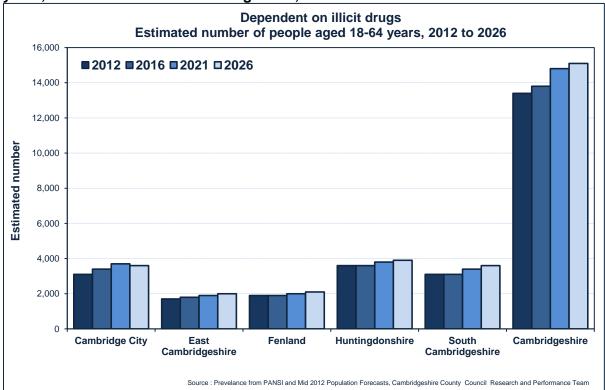


Figure 30: Projected numbers of people with drug dependence, people aged 18 to 64 years, local authorities in Cambridgeshire, 2012 to 2026

Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

Table 31: Changes in projected numbers of people with drug dependence compared
with 2012, local authorities in Cambridgeshire, 2012 to 2026

Local Authority	Estimated number			Change (number)			% change 2012 to	
	2012	2016	2021	2026	2012 to 2016	2016 to 2021	2021 to 2026	201210
Cambridge City	3,100	3,400	3,700	3,600	300	300	-100	16.1%
East Cambridgeshire	1,700	1,800	1,900	2,000	100	100	100	17.6%
Fenland	1,900	1,900	2,000	2,100	0	100	100	10.5%
Huntingdonshire	3,600	3,600	3,800	3,900	0	200	100	8.3%
South Cambridgeshire	3,100	3,100	3,400	3,600	0	300	200	16.1%
Cambridgeshire	13,400	13,800	14,800	15,100	400	1,000	300	12.7%

Note : Total may not agree due to rounding

Source: PANSI and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

#### **Autism Spectrum Conditions (ASC)**

The latest epidemiological studies on ASC are primarily focussed on those under the age of 18, potentially due to the fact that detection of cases in children is more straight-forward as younger individuals can be observed more easily (by parents or teachers)<sup>50</sup>. As there is currently limited information on adult prevalence of ASC it is worth noting that current studies suggest that the prevalence of ASC in children is around  $1\%^{51,52}$ , with figures showing a 0.39% (95% CI 0.29 to 0.48) prevalence of childhood autism, and 0.77% (95% CI 52.1 – 102.3) prevalence of other ASCs. No further breakdown of the sub-classifications of ASC is available, potentially due to the fact that there remains controversy regarding the diagnosis of the different conditions.

The best current data regarding adult (18 years+) ASC prevalence is from a 2012 report 'Estimating the Prevalence of Autism Spectrum Conditions in Adults'<sup>53</sup>. This report used data from the 2007 Adult Psychiatric Morbidity Survey (APMS 2007), which was representative of the population living in private households, combined with results from a 2010-2011 study of the prevalence of autism among adults with learning disabilities living in private households and communal care establishments (a sub-group which was not included in the APMS 2007).

The overall prevalence of ASC, combining the APMS 2007 and the learning disability study was 1.1% of the adult population. The prevalence figure varied significantly between men (2.0%) and women (0.3%). Figure 32 and Table 33 uses these prevalence figures to estimate the numbers of adults living with an ASC in Cambridgeshire.

The prevalence of autism among those with learning disabilities was significantly higher; 35.4% for those living in private households with learning disabilities and 31.0% among adults with learning disabilities living in communal care establishments.

The prevalence data defines individuals as having, or not having ASC and does not provide any information on the sub-classification or the severity of the condition, or the impact the condition has on each individual. As the condition can vary in severity and affect people in such different ways the information has to be read with caution in use with any service provision planning. Those on different parts of the spectrum may have very different needs, and these prevalence figures are based on criteria for medical diagnosis.

<sup>&</sup>lt;sup>50</sup> Brugha, T., McManus, S., Meltzer, H. Smith, J. Scott, F. J., Purdon S. et al. (2007) Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007. NHS Information Centre

 <sup>&</sup>lt;sup>51</sup> Baird, G., Simonoff, E., Pickles, A., Chandler, S. Loucas, T., Meldrum, D., et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). Lancet

 <sup>&</sup>lt;sup>52</sup> Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Fiona, E. (2009) Prevalence of autismspectrum conditions: UK school-based population study. The British Journal of Psychiatry

 <sup>&</sup>lt;sup>53</sup> Brugha, T., Cooper, S. A., McManus, S., Purdon, S., Smith, J., Scott, F.J. et al. (2012) Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey. The Information Centre

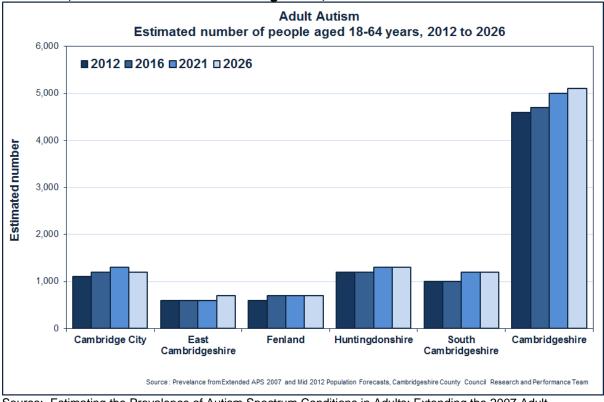


Figure 32: Projected numbers of people with autistic spectrum condition compared with 2012, local authorities in Cambridgeshire, 2012 to 2026

Source: Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey. The Information Centre and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

Table 33: Changes in projected numbers of people with autistic spectrum condition
compared with 2012, local authorities in Cambridgeshire, 2012 to 2026

Local Authority	Estimated number			Change (number)			% change 2012 to	
	2012	2016	2021	2026	2012 to 2016	2016 to 2021	2021 to 2026	2012 10
Cambridge City	1,100	1,200	1,300	1,200	100	100	-100	9.1%
East Cambridgeshire	600	600	600	700	0	0	100	16.7%
Fenland	600	700	700	700	100	0	0	16.7%
Huntingdonshire	1,200	1,200	1,300	1,300	0	100	0	8.3%
South Cambridgeshire	1,000	1,000	1,200	1,200	0	200	0	20.0%
Cambridgeshire	4,600	4,700	5,000	5,100	100	300	100	10.9%

Note: Total may not agree due to rounding

Source: Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey. The Information Centre and Mid 2012 Population Forecasts, Cambridgeshire County Council Research and Performance Team

#### Suicide

Suicide rates in Cambridgeshire are similar to those in England as a whole (Figure 34).

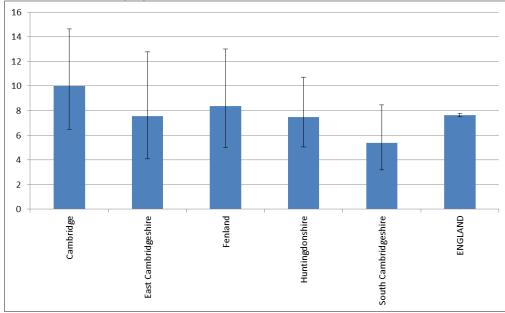


Figure 34: Directly age-standardised mortality rates per 100,000 population aged 15+ for suicide and injury undetermined, 2010-12

Further information on suicide will be available in the 'Joint Cambridgeshire and Peterborough Suicide Prevention Strategy 2014 – 2017' due to be published soon.

## 3.6 Health service activity (GP and Hospital activity) and unpaid care

#### **GP** Activity

There is very little information about the prevalence of the conditions covered in this report in general practice work. The only information available across the NHS concerns the treatment and prevalence of depression. The following information gives details of this data as it provides useful context for thinking about common mental health disorders and how treatment of these may interact with the conditions of interest.

Figure 35 shows the prevalence of depression in each general practice in Cambridgeshire according to the Quality and Outcomes Framework (QOF) records of each practice. Depression is commonly experienced by people with other mental health disorders including autism, personality diagnosis and dual diagnosis. It shows marked variation, with the reported prevalence in some practices being seven times higher than that in others. While this may reflect variation in underlying prevalence, differences in diagnostic behaviour and recording is also likely to have contributed to this six fold variation.

The three conditions of interest in this report are not part of QOF reporting.

Source: HSCIC

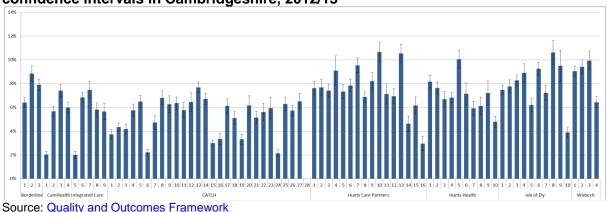


Figure 35: Reported prevalence of depression, by general practice and LCG with confidence intervals in Cambridgeshire, 2012/13

Analysis by local commissioning group shows substantial and statistically significant differences (Figure 36).

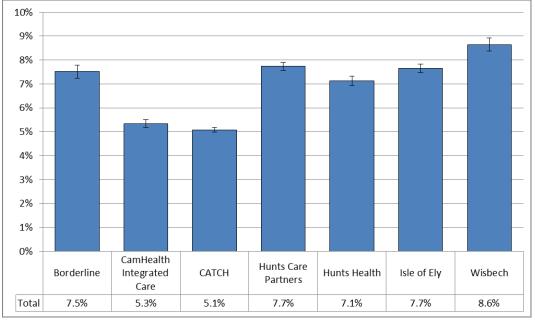
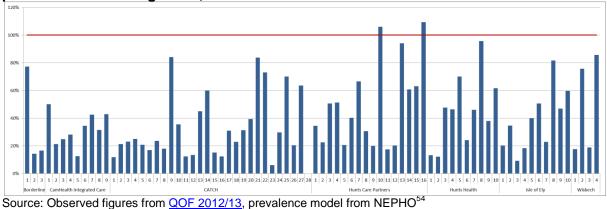


Figure 36: Reported prevalence of depression, by LCG in Cambridgeshire, 2012/13

Source: Quality and Outcomes Framework

We compared the number of people with depression recorded by each practice with the number we would expect based on the age and sex of the practice's patients. Figure 37 shows the ratio of the first number to the second for depression; a ratio of less than one suggests that there are patients with the condition in the practice who are not diagnosed, or whose diagnosis is not recorded.



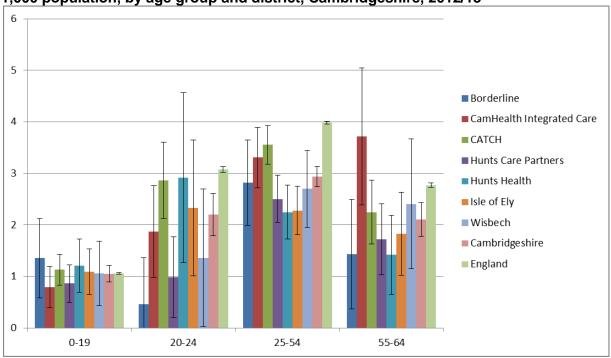
## Figure 37: Ratios of recorded to expected numbers of adults with depression, practices in Cambridgeshire, 2012/13

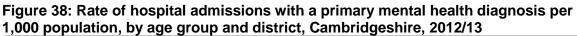
The variation in recorded prevalence of depression is reflected in widely different ratios of observed to expected prevalence figures. There are wide variations between practices in the proportion of patients with depression who are diagnosed and recorded by their primary care team. Very few practices have identified all or nearly all their patients with the condition, many have only found half, and a large number as few as a fifth. Depression occurs in people with autistic spectrum condition, personality disorder and dual diagnosis, so this under-diagnosis of depression is relevant to their needs. This is an important missed opportunity to help people with a distressing but highly treatable condition.

#### **Hospital Activity**

Figure 38 shows the rate of mental health admissions in children and adults in different parts of Cambridgeshire. There are differences between areas; these may be due to chance, recording, proximity to hospital and other factors. Rates in localities closer to Cambridge appear somewhat higher. Because the local commissioning groups have different boundaries from district councils, no direct comparisons with need can be made. Rates in Cambridgeshire are lower than those in England.

<sup>&</sup>lt;sup>54</sup> Mental Health Observatory Brief 4 - Estimating the Prevalence of Common Mental Health Problems (<u>http://www.nepho.org.uk/mho/briefs/</u>). The NEPHO model is for ages 16 to 74 years only. We have extrapolated the prevalence in people aged 70 to 74 years to people over 74 years. QOF records cannot be analysed for specific age-groups, such as adults of working age.

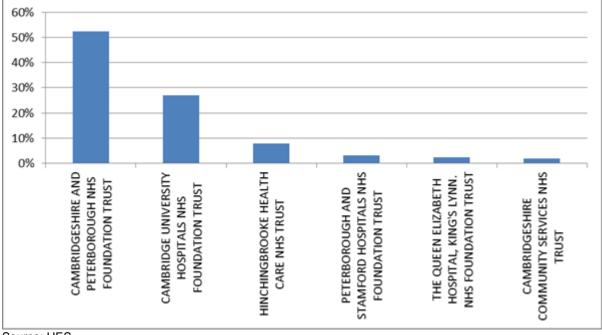




Source: HES (population figures Cambridgeshire County Council)

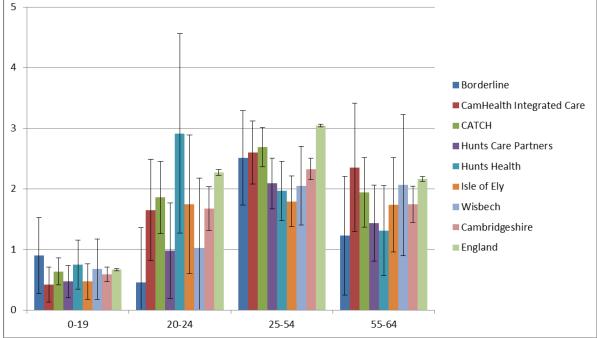
Figure 39 shows the rate of mental health admissions children and adults in different parts to different providers in Cambridgeshire. A quarter of admissions are to Cambridge University Hospitals Trust.

Figure 39: Proportions of hospital admissions with a primary mental health diagnosis, by provider, people aged 0 to 64 years, Cambridgeshire, 2012/13



Source: HES

Figure 40 shows the rate of emergency mental health admissions in children and adults in different parts of Cambridgeshire. Again there is marked variation with higher rates in and around Cambridge, and rates lower in Cambridgeshire than in England.



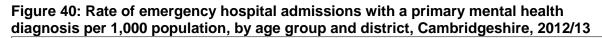


Figure 41 shows the rate of emergency mental health admissions children and adults in different parts to different providers in Cambridgeshire. A largest share of these admissions is to Cambridge University Hospitals Trust.

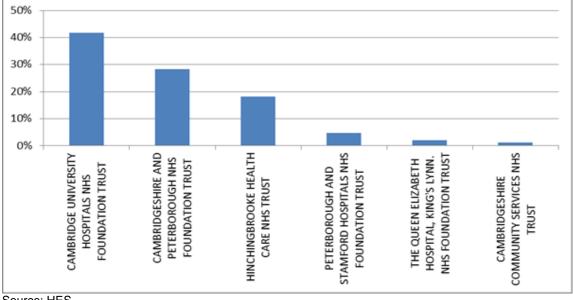


Figure 41: Proportions of emergency admissions with a primary mental health diagnosis, by provider, people aged 0 to 64 years, Cambridgeshire, 2012/13

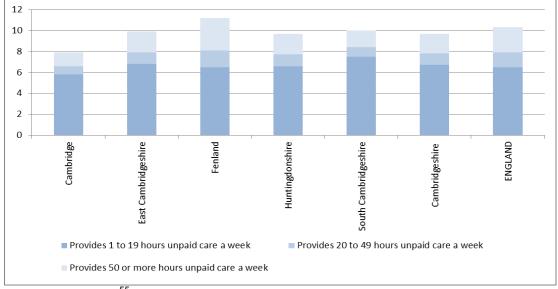
Source: HES

Source: HES (population figures Cambridgeshire County Council)

#### **Unpaid Care**

Figure 42 shows the proportion of people who provide unpaid care. Most parts of Cambridgeshire are close to the national average of 10%, but the proportion is slightly higher in Fenland and lower in Cambridge.





Source: Census 2011<sup>55</sup>

<sup>&</sup>lt;sup>55</sup> <u>http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/rft-table-ks403ew.xls</u>

#### Summary

- 1. The population of Cambridgeshire is expected to grow by 19% between 2012 and 2026, including growth in nearly all age-groups and all local authority areas.
- 2. Cambridgeshire's population is more affluent and less ethnically diverse than that of England, but social isolation is no less common.
- 3. Most risk factors for poor mental health show similar patterns of prevalence across Cambridgeshire, though in some cases the Cambridgeshire population shows a lower risk profile. There are also areas within the county where risk factors are concentrated, such as Fenland.
- 4. For the specific conditions considered in this report, by 2026, there are expected to be about 1900 people in the County with borderline personality disorder, about 1500 with anti-social personality disorder and about 5,100 with ASC. Projecting the prevalence of dual diagnosis is more complicated because the age-specific prevalence is not constant. No projected prevalence of dual diagnosis is available, but the rising prevalence of excessive drinking suggests that it is likely to become more common amongst a proportion of this group<sup>56</sup>.
- 5. An increase in prevalence of common mental health disorders as well as those conditions specific to this report, is predicted across all Cambridgeshire districts, with growth in numbers concentrated in Cambridge City especially.
- 6. The number of people affected by mental illness in Cambridgeshire is expected to increase in line with the population. In Cambridgeshire, many people with depression have not been diagnosed and recorded by their primary care teams, which reflects a national trend. This means they cannot receive the treatment and support they need. This suggests that there is unmet mental health need within the population. In addition, depression occurs in people with ASC, personality disorder and dual diagnosis, so this under-diagnosis of depression is relevant to their needs

<sup>&</sup>lt;sup>56</sup> Home Office. The Government's Alcohol Strategy. March 2012. <u>www.gov.uk/government/publications/alcohol-strategy</u>

## 4. Service map

In this section of the report, we present information about services available in Cambridgeshire for people with the mental disorders covered by this report. We first describe the services specifically intended for people with these disorders, then provide outline information on services aimed at a wider range of people which may include those with these disorders. Many of the primary care and specialist services for mental health people will treat those with the mental disorders covered here as part of a wider general service. However, this is not always specified in contract arrangements, service descriptions or budgets, and so may have a less obvious profile in reports such as this.

## 4.1 Autism spectrum conditions (ASC)

#### Cambridge and Peterborough Foundation Trust

Autism in adults was recognised as a local priority in the Cambridgeshire and Peterborough Commissioning Strategy for the Mental Health and Well-Being of Adults of Working Age 2013 – 2016. Specifically, the strategy called for 'improved access to diagnosis and local support for people with the life-long conditions autism and ADHD'.

Cambridgeshire and Peterborough NHS Foundation Trust's 2010 Guide to mental healthcare pathways does not include a pathway for adults with autism.

Cambridge and Peterborough Foundation Trust (CPFT) provides a diagnostic service only for autism spectrum conditions. The service is intended to:

- Improve diagnostic accuracy.
- Improve identification of coexisting conditions.
- Improve health-related quality of life.
- Improve functioning in social/occupational/educational settings.
- Improve outcomes for co-existing conditions such as depression, anxiety, substance mis-use and para-suicidal behaviours.
- More effective, transparent and integrated care pathways.

It aims to:

- Provide diagnostic excellence through evidence-based multi-disciplinary assessment for the presentation of Asperger syndrome (AS) and high functioning autism (HFA) in adults aged 18 years and over.
- Clearly identify adults with AS and HFA.
- Carry out specialised needs and risk assessment for adults with AS and HFA.
- Provide comprehensive reports that detail recommendations of future need and preferences in a highly personalised way beyond diagnostic requirements.
- Undertake collaborative and consultative work with commissioners and others in the development of provision locally.
- Support training and skill sharing to services and others that work with adults with autism.
- Influence local leadership with regard to providing services to adults with autism and the development of integrated care pathways.

Responsibility for clients ends with the diagnosis, whereupon they are referred back to their GP with recommendations. The service does not offer follow-up consultations.

An autism clinical pathway is under development.

NICE's clinical guideline includes the following pathway (Figure 43), which may form the basis for local work:

**NICE** Pathways Pathway information v Into practice v Guidance 🗸 Quality standards 🗸 Save & print v Management and support for adults with autism Autism Person with autism, their family, partner or carers Identifying the correct Support for families, interventions partners and carers Monitoring interventions Interventions for autism Interventions for coexisting Interventions for challenging behaviour mental disorders

#### Figure 43: NICE Pathways - Management and support for adults with autism

Employment support is important for people with autism. There are several social training enterprises in Cambridge that run courses and provide work experience opportunities. These include horticulture, catering and cookery, woodwork, basic skills, retail and office skills and using the computer.

Some large private sector employers are positive about employing people with disabilities. Cambridge is home to several large public sector organisations that are well placed to employ more people with disabilities. In addition, an Adult Placement Scheme in Huntingdonshire, which is part of the Learning Disability Partnership, has been successful in supporting people with learning disabilities into employment.

#### Transition

Transition is the process of moving from childhood into adulthood. The transition between children's and adult social care and health services is regularly cited as one of the most difficult experiences for young people and their families. Poor transition processes are associated with poor health and social care outcomes. The issue of transition is particularly relevant to those with autistic spectrum condition as this is usually diagnosed in childhood. The services and support that they and their families receive are commissioned, organised and delivered via a different team. As they become adults, their needs change and the support that they need is commissioned and delivered by different organisations and individuals.

A multi-agency protocol for transition in Cambridgeshire was launched in 2009, for young people likely to meet the eligibility criteria for social care support in adult life. The Enhancing Transitions in Cambridgeshire Project was commissioned by the Transitions Partnership Board to bring children and young people's services and adults commissioning processes together. In addition to £85,000 of transitions development funding, a grant of £58,000 was awarded to the Transitions Team by the Transitions Support Programme, to invest in this work.

In 2012, in consultation with young people and parent carers, Cambridgeshire County Council developed a vision for young people in transition. A health passport has been developed in Community Child Health for children attending special schools in the area and is available on SystemOne (a clinical information system). The generic information populates automatically from records held on the system. The passport is currently being completed, led by the special school nurse and used for any child transitioning into adult services. The next stage of development will be to extend this to the time of entry to special schools, where it can be accessed and populated by the health visitor and other health professionals involved in the child's care. Further anticipated development would be obtaining parental consent to share information with social care so that it can feed into a single health and education plan.

#### Cambridgeshire County Council

Cambridgeshire County Council (CCC) aims to commission services that meet a range of needs including people who also may be on the autistic spectrum, have behavioural needs or some level of physical disability. Many of its current residential care, supported living, day opportunities, advocacy, floating support and other services will therefore be accessible to people on the autistic spectrum. The Council is also working to make universal services such as community health more accessible to people on the autistic spectrum as well as increasing employment opportunities for this group.

The County Council funds two Autism Support Workers to provide specialist support to adults with autism who do not have a learning disability or mental health diagnosis. For example the support worker will provide support to people on the spectrum and family carers who may not necessarily be eligible for social care, but who may need support around housing, employment, health or other issues. The Council believes that support at an early stage may offset or delay the need for more intensive support later on.

The council has also developed a new training programme involving an "expert by experience". This will be offered to all CCC employees and commissioned social care services staff, and will commence in October 2014.

#### 4.2 Personality disorder

The CPFT service provides care for people aged 18 to 65 years with a primary diagnosis of personality disorder currently treated within secondary care, but requiring specialist input. Patients are selected who have high levels of risk and impairment, with priority given to those having extreme presentations formerly requiring out-of-area placements. These often have co-morbidity such as substance misuse and psychosis. Patients must be willing to engage with the complex case service. Exclusion criteria include:

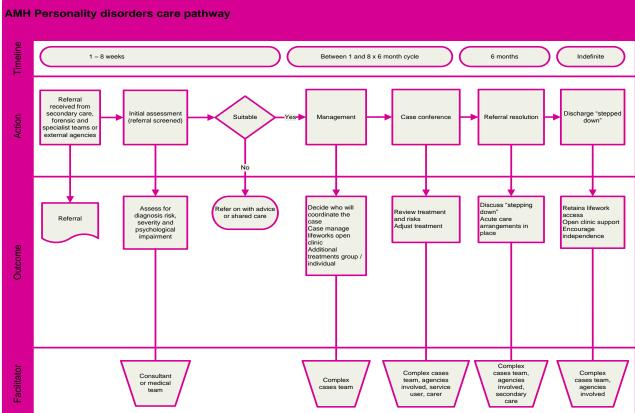
- Treatment and support can be managed in primary or secondary care.
- Service user unwilling to accept intervention from the complex case service.
- Predominantly drug or alcohol dependent.
- High risk of harm to others.
- Prominent organic impairment such as severe learning disability etc.

The service comprises:

- Engagement and psycho-education.
- Risk assessment and management.
- Socialisation and peer support via attendance of Lifeworks.
- Access to emergency clinic and case management as part of the weekday outpatient service.
- Therapeutic interventions including multi-modal group and individual therapy.
- Liaison and partnership work with secondary care.
- Probation work.

Cambridgeshire and Peterborough NHS Foundation Trust's 2010 *Guide to mental healthcare pathways* includes a pathway (Figure 44) for people with personality disorder, though there are no specific interventions included for them.

All the pathways shown in this report are under review and Cambridgeshire and Peterborough Foundation Trust (CPFT) are currently considering options for increased access to the Personality Disorder pathway, working with MIND, HealthWatch and other representative groups.



#### Figure 44: AMH Personality disorder care pathway

Source: Cambridgeshire and Peterborough Foundation NHS Trust

The most recent information shows 140 referrals to the service in the first nine months of 2013/14. There were 132 completed care pathways, though these may not be the same patients.

#### 4.3 Dual diagnosis

Dual diagnosis was recognised as a local priority in the Cambridgeshire and Peterborough *Commissioning Strategy for the Mental Health and Well-Being of Adults of Working Age* 2013 – 2016. Specifically, the strategy called for "Clear pathways for dual diagnosis case management."

Drug and alcohol services are commissioned by Cambridgeshire County Council, under the advice of the Drug and Alcohol Action Team. CPFT provides mental healthcare including IAPT, Inclusion provides the drug and alcohol treatment service.

Cambridgeshire has a draft dual diagnosis strategy, published in March 2013 and under review. The provider organisations and other agencies agreed a dual diagnosis working protocol. It describes the joint approach that will be taken by services in respect of Cambridgeshire residents 18 to 65 years old who require treatment and/or support for co-existing mental health and substance misuse problems.

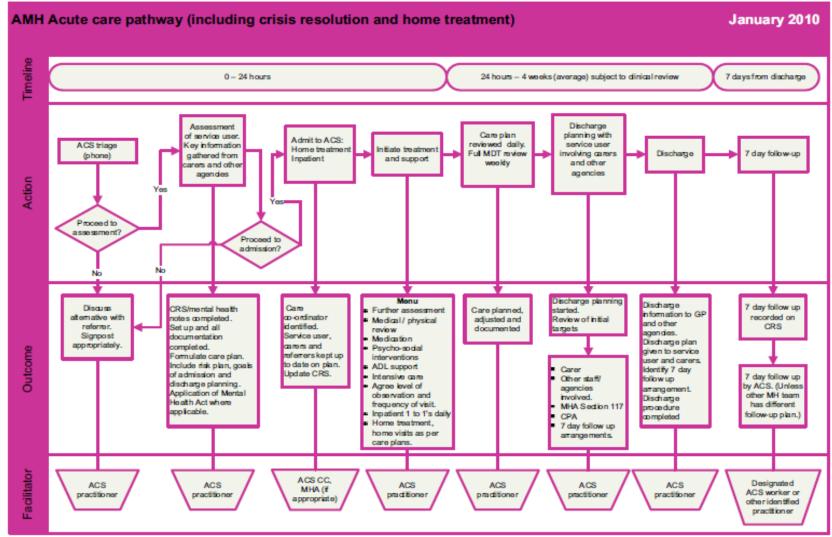
The dual diagnosis care pathway stipulates an initial assessment to establish the severity of the client's mental health and substance misuse problems. It outlines three outcomes for this assessment:

- Severity of substance misuse high and severity of mental illness high: dual diagnosis confirmed pathway.
- Severity of substance misuse low and severity of mental illness high: mental health pathway.
- Severity of substance misuse high and severity of mental illness low: substance misuse pathway.

Although these arrangements often work well, there are indications that clients sometimes receive an incomplete or disjointed service because of difficulties in arranging fully coordinated care. Their problems may not be fully diagnosed at the inception of care or the right services may not be available. A reported particular problem is an unwillingness of any agency to take the lead in clients with dual diagnosis<sup>57</sup>.

CPFT's 2010 *Guide to mental healthcare pathways* includes an acute care pathway which is intended for use in people with a dual diagnosis of serious mental illness and a learning disability or drug and alcohol problem. There are no specific interventions included in the pathway (Figure 45).

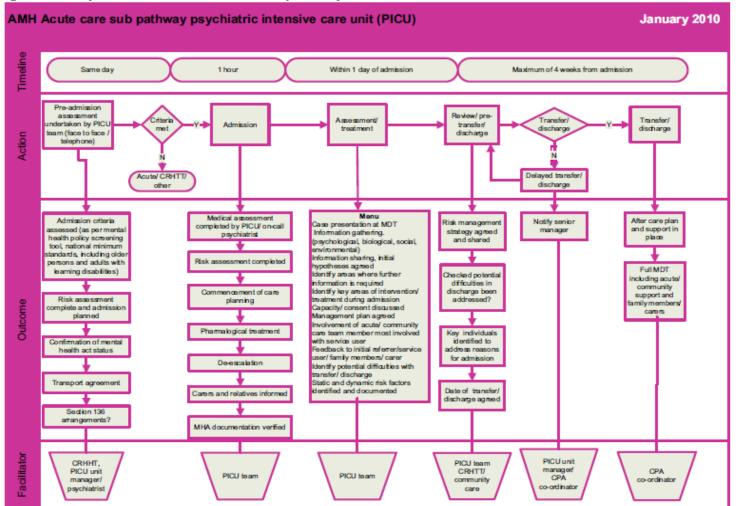
<sup>&</sup>lt;sup>57</sup> Cambridgeshire Joint Adult and Older People Mental Health JSNA Steering Group members, Workshop session. 11<sup>th</sup> February 2014.



#### Figure 45: Acute care pathway

Source: Cambridgeshire and Peterborough Foundation NHS Trust

The psychiatric intensive care unit pathway is also aimed at this client group, but also contains no specific interventions (Figure 46).



#### Figure 46: Psychiatric intensive care unit pathway

Source: Cambridgeshire and Peterborough Foundation NHS Trust

#### 4.4 Supporting Recovery

Recovery is often used to describe the process a person with mental health issues goes through to move forward in their life. For some people this can be about returning to a state of feeling well and content, for others it can be about rebuilding their life after a period of illness and understanding more about how to manage problems related to their health and lifestyle.

For many people, recovery is about achieving the best quality of life possible whilst living with ongoing symptoms. The concept of recovery is not the same as 'cure', it is for the person to choose whether to enter recovery and to define and lead this. Recovery does not depend on any one factor such as being in work. It is individual and there should be no benchmark of what someone's recovery should look like or how quickly they need to achieve goals.

CPFT was one of six demonstration sites for Implementing Recovery Organisational Change (ImROC), a joint sponsored project by the Department of Health and the NHS Confederation. Their success in embedding a recovery approach and in making good progress in many of the key elements of recovery-focused practice has been highlighted nationally, in particular, in the training and employment of peer workers. 60 peers with 'lived experience' of mental health problems have been trained and more than 50 have been appointed to positions within CPFT. This ongoing programme of training and integration supports diversity in the workforce and recognises the importance of lived experience in delivery of mental health services.

In addition, the Trust has developed the model of a Recovery College. This is a collaborative, educational learning environment for people who receive services from Cambridgeshire and Peterborough NHS Foundation Trust and partner organisations, their supporters, staff and students. The college prospectus offers a range of recovery focused education through peer-led courses and workshops. All the courses are co-produced and co-delivered, involving at least one person with lived experience of mental health challenges alongside an education professional. They aim to:

- Support people to receive care which is, as far as possible, 'self-directed' and reflects their preferred goals and outcomes.
- Help people to use their own experience and expertise to manage their symptoms, in partnership with professionals.
- Help more people with serious or severe mental health problems to be in employment.
- Help more people with serious mental health problems to be living in appropriate accommodation.

#### 4.5 Other services

#### Primary care

Primary care plays a critical role in the care of people with mental illness, providing most of their care and treatment. This includes diagnosing mental health problems, providing support to the patient and family, prescribing medication and referring where necessary.

#### Liaison psychiatry

Addenbrooke's liaison psychiatry service provides specialist mental health assessment and treatment for inpatients and outpatients of Addenbrooke's Hospital who are working age adults (17 to 64). The service aims to provide the patients and clinicians of the general hospital with an expert service that is evidence based and responsive to needs, so that patients are assessed and treated promptly, and when appropriate, diverted to other mental health and community services. Liaison psychiatry is now also available at Hinchingbrook Hospital.

#### Improving Access to Psychological Therapies programme

The Improving Access to Psychological Therapies (IAPT) programme supports the frontline NHS in implementing National Institute for Health and Clinical Excellence (NICE) guidelines for people suitable for talking therapies. The programme is intended mainly for people with depression and anxiety disorders, but may be used more widely.

#### Advice and Referral Centres (ARCs)

The advice and referral centres provide a single point of access into services. Referrals are received and triaged prior to signposting to the most appropriate service. If referrals are complex and cannot be processed via telephone or triaging, gateway workers undertake face to face assessments.

The ARC provides GPs, nurses, and other local medical professionals, with advice, support and information. They are the main channel of mental health prevention information, specialist advice to GPs, self-management, signposting and initial triaging of referrals will be provided.

The service will collect a range of data regarding referrals into the service to include; volume, treatment options and engagement rates, and signposting.

#### Attention deficit hyperactivity disorder service

The attention deficit hyperactivity disorder (ADHD) service provides a specialist diagnostic service and a range of pharmacological and psychosocial interventions for adult ADHD to the adult population of Cambridgeshire and Peterborough. The small multidisciplinary team is led by a consultant psychiatrist. The service is of relevance as people with personality disorder and autism can also have ADHD.

The assessment process is based on a collaborative clinic model and is highly personalised. The assessment tools and focus of clinical experience is built around the individual and includes taking a detailed personal and developmental history. The diagnostic milieu includes mental wellbeing, neuropsychological, social cognition, mood and emotional assessments. The service uses evidence based standardised assessment instruments for adult ADHD. The adult ADHD clinic provides two pathways for adults with ADHD as part of existing pathways: a primary care pathway for adults with possible or previously diagnosed ADHD without or with mild co-morbidity referred by GPs, and a tertiary care pathway for adults with possible or previously diagnosed ADHD and moderate to severe co-morbidity.

There are a range of third sector providers contracted by the CCG and also Cambridgeshire County Council. Their services are described below. These services are commissioned for adults with mental health disorders, but none are exclusively for adults with autism, personality disorder or dual diagnosis.

The table<sup>58</sup> below illustrates where the services can be accessed in Cambridgeshire.

Type of service	Cambridge	East Cambridgeshire	Fenland	Huntingdon	South Cambridgeshire	HMP Littlehey
		•			•	
Counselling	Mind Relate Choices	Relate Choices	Vineyard Relate Choices	Mind Relate Choices	Mind Relate Choices	
IAPT	CPFT <sup>59</sup> GTC <sup>60</sup> RFET <sup>61</sup>	CPFT RFET	Vineyard Mind CPFT RFET	Mind CPFT RFET	CPFT RFET	Mind
Wellbeing	Mind Lifecraft	Mind Health4Life Red2Green	Richmond Fellowship	Mind	Mind	
Employment	Richmond Fellowship	Richmond Fellowship Red 2 Green	Richmond Fellowship	Richmond Fellowship	Richmond Fellowship	
Family support			Fenland Family Support			
Groupwork	CPFT GTC Cambridge Counselling Service	CPFT	CPFT	CPFT	CPFT Cambridge Counselling Service	
Mental Health Advocacy	CIAS	CIAS	CIAS	CIAS	CIAS	

#### Mind

Mind provides several services in Cambridgeshire funded by the NHS. They include:

Changing Lives service
 This service is linked to the Improving Access to Psychological Therapies
 programme. The services provided reflect the focus of the programme in helping
 people with mental health problems improve their general health and wellbeing and
 promotes social inclusion and economic productivity. The particular focus of the
 service is people who struggle to access mainstream mental health services provided
 by NHS statutory providers.

 <sup>&</sup>lt;sup>58</sup> Cambridgeshire Joint Adult and Older People Mental Health JSNA Steering Group members, Meeting 11<sup>th</sup> March 2014.
 <sup>59</sup> OPET Combridge and Peterhonouch Foundation NUC Trust

<sup>&</sup>lt;sup>59</sup> CPFT = Cambridge and Peterborough Foundation NHS Trust

<sup>&</sup>lt;sup>60</sup> GTC = Group Therapy Centre

<sup>&</sup>lt;sup>61</sup> RFET = Richmond Fellowship Employment and Training

• Counselling Service

Mind provides a counselling service in the Cambridge and Huntingdon areas, complementing other local provision for people with mental health problems for whom counselling would be a beneficial intervention.

- Service User Engagement Worker Mind hosts a service user engagement worker on behalf of four local voluntary organisations providing mental health services. This co-ordinates representative service-user input into local commissioning work-streams.
- Groups for people with personality disorders These have been available since 2006, and operate without specific external funding. Referrals have increased by 60% in the last 18 months.

Mind in Cambridgeshire receive funding from Cambridgeshire County Council and Cambridgeshire and Peterborough Clinical Commissioning Group for the service user engagement project.

#### Red2Green

Red2Green is a third-sector organisation which prepares people for training and employment. The purpose of the service will be to provide local activities, community groups and clubs, to a wide range of clients including, isolated people, older people and those with a wider range of diagnosable mental health concerns for the local population as is practicable within the constraints of the level of the contract value.

#### **Richmond Fellowship**

The Richmond Fellowship is an employment support service for people accessing psychological therapies as part of the Cambridgeshire and Peterborough Increased Access to Psychological Therapies service. It is available for those struggling to stay in work because of their mental health problems. Although autism, personality disorder and dual diagnosis may not the main focus of the service, the service might be of use to people with those diagnoses. As part of the service, employment support workers provide skills-based interventions, information, advice, guidance and other practical support to help people receiving IAPT services to:

- Retain employment.
- Exchange employment for another more suitable job role.
- Return to employment from a period of sickness absence from work.
- Access employment for the first time or after a substantial period of absence from the labour market.

The Richmond Fellowship funding comes from Cambridgeshire County Council for mental health day services and their employment support work, and they are also funded by the Cambridgeshire and Peterborough Clinical Commissioning Group.

#### Relate

Relate provides relationship counselling and/or psychosexual therapy for individuals and couples who either self refer or are referred by their GPs.

#### Choices

This service provides specialist counselling services for victims and survivors of sexual abuse.

Choices receive funding from Cambridgeshire County Council and Cambridgeshire and Peterborough Clinical Commissioning Group for counselling services for victims of abuse.

#### Community Counselling Services

This service offers up to twelve sessions of counselling in the community for residents of North Cambridge. The service also offers psycho-educational group courses to assist clients with anger management and assertiveness and self-esteem.

#### Fenland Family Support Centre

The centre provides counselling services for families in the Fenland area. The service includes self-help, providing help for individuals and families in crisis, providing work creation, community development, information and education.

#### The Vineyard

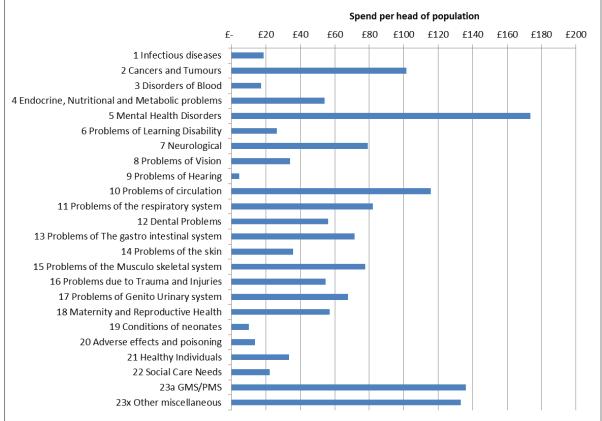
This service provides specialist counselling in the Fenland area. Part of the local IAPT service, it offers evidence-based psychological therapy to people suffering from depression and anxiety, alongside appropriate anti-depressant medication and other possible interventions.

#### 4.6 Cambridgeshire and Peterborough Clinical Commissioning Group expenditure

The CCG's total expenditure on adult mental health in 2013-2014 was £48,142,499 per annum, divided between the statutory (£46,844,417) and third sectors (£1,298,082). This is for all categories of patient, not just for those with the conditions of interest in this report. It excludes accident and emergency and prescribing expenditure which cannot be attributed uniquely to the specific adult mental health groups concerned in this report. It also excludes the time and associated costs of GP support and care provided to adults who use mental health services and their families.

Figure 47 shows the spending by the NHS in Cambridgeshire per head of population on different categories of patient in 2012/13. £174 per person per year was apparently spent on mental health programmes, 3% less than the £180 spent in 2011/12 and 18% less than the £213 per head spent on mental health programmes in England as a whole. This information is based on programme budgets. The definitions and coding practice used to compile the figures may differ between parts of the NHS and between years, with implications for the reliability of these comparisons. More analysis of the reasons for the differences would be of value, and no definitive conclusions should be drawn from this data given the variation in coding and calculations across the NHS.

# Figure 47: Spend per head of population by programme budget categories, Cambridgeshire, 2012/13



Source: Department of Health<sup>62</sup>

The recent fundamental review of the NHS funding allocation formula found that in 2013/14, Cambridgeshire and Peterborough CCG's funding per head is £961. This is for all health services including mental health. This is the lowest in East Anglia, 9% less than the average of £1,054 per person<sup>63</sup>. The CCG is one of the 11 health economies in England with the most severe financial challenges.

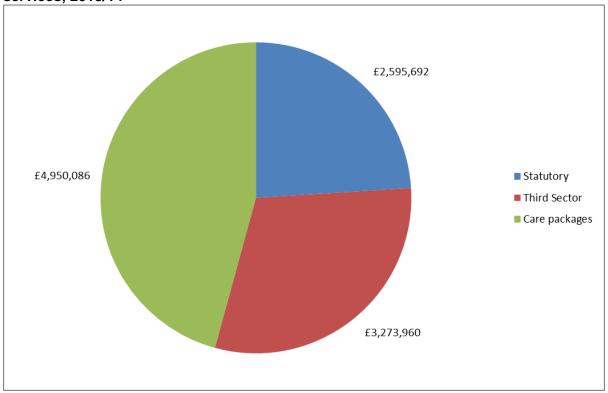
## 4.7 Cambridgeshire County Council Expenditure

Figure 48 shows the County Council's expenditure on adult mental health, divided between the statutory and third sectors and care packages. This is for all categories of patient, not just for those with the conditions of interest in this report.

Care packages are packages bought following an assessment of need. Of the £4.9m spent on care packages, £923,993 was spent on nursing placements and just under £2.6m on residential placements.

<sup>&</sup>lt;sup>62</sup> <u>http://www.networks.nhs.uk/nhs-networks/health-investment-network/news/2012-13-programme-budgeting-</u> <u>data-is-now-available</u>

<sup>&</sup>lt;sup>63</sup> Fundamental review of allocations policy. August 2013 NHS England.



# Figure 48: Cambridgeshire County Council's expenditure on adult mental health services, 2013/14

Source: Cambridgeshire County Council

## 5. Activity analysis

Needs assessment depends on understanding the present pattern of service use and how resources are directed. For NHS mental health services, the most appropriate source for these is the mental health minimum dataset, which contains details of each episode of care provided through the NHS, anonymised to protect patient confidentiality. No access to this dataset was possible within the four-month timescale of this project. This report therefore contains no information on the volume or cost of mental health services for adults apart from some limited activity information from key performance indicators provided by Cambridgeshire CCG.

## 6. Relevant NICE Guidance.

We have summarised the relevant NICE guidance (clinical guidelines, public health guidance and quality standards) in Table 49 below. In addition, the remainder of the chapter attempts to summarise the key points from the most pertinent guidelines. However, for reasons of brevity, this does not capture the very detailed content of each guideline such as which diagnostic tests to use, or the sequence and type of psychotherapy that should be offered and by whom.

Table 49: Relevant NICE Guidance	Areas covered by recommendations
General:	
Behaviour change: individual approaches PHG49, 2014 <u>http://guidance.nice.org.uk/PH49</u>	<ol> <li>Local behaviour change commissioning policy, strategy, interventions and programmes</li> <li>Organisation policies, strategies, resources and training all support behaviour change</li> <li>Commission high quality, effective behaviour change interventions</li> <li>Deliver very brief, brief, extended brief and high intensity behaviour change interventions and programmes</li> <li>Ensure behaviour change is maintained for at least a year</li> <li>Training for all staff involved in helping to change people's behaviour</li> <li>Monitoring and evaluation of behaviour change interventions</li> </ol>
Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services CG136, 2011 <a href="http://www.nice.org.uk/CG136">http://www.nice.org.uk/CG136</a>	<ul> <li>Care and support across all points on the care pathway</li> <li>Access to care</li> <li>Assessment</li> <li>Community Care</li> <li>Assessment and referral in a crisis</li> <li>Hospital care</li> <li>Discharge and transfer of care</li> <li>Assessment and treatment under the Mental Health Act</li> </ul>
Service user experience in adult mental health: Quality Standard QS14, 2011 http://www.nice.org.uk/guidance/QS14	Covers improving the experience of people using adult NHS mental health services (excluding mental health service users using NHS services for physical health problems, or the experiences of families or carers of people using NHS services specifically).

Promoting mental wellbeing at work PH22, 2009 http://guidance.nice.org.uk/PH22	
Violence: the short-term management of disturbed/ violent behaviour in in-patient psychiatric settings and emergency departments. CG25, 2005 http://www.nice.org.uk/CG25	<ul> <li>Environment and alarm systems</li> <li>Prediction: antecedents, warning signs and risk assessment</li> <li>Training</li> <li>Working with service users</li> <li>De-escalation techniques</li> <li>Observation</li> <li>Physical interventions</li> <li>Seclusion</li> <li>Rapid tranquillisation</li> <li>Post-incident review</li> <li>Emergency departments</li> <li>Searching</li> </ul>
Personality Disorder	
Borderline personality disorder: treatment and management NICE CG78, 2009 http://www.nice.org.uk/CG78	<ul> <li>Key priorities for implementation</li> <li>Person-centred care</li> <li>Principles for working with people with borderline personality disorder</li> <li>Recognising and managing borderline personality disorder in primary care</li> <li>Assessment and management by community mental health services</li> <li>Inpatient services</li> <li>Organising and planning services</li> </ul>
Antisocial personality disorder: treatment, management and prevention. NICE CG77, 2009/2013 http://www.nice.org.uk/CG77	<ul> <li>General principles for working with people with antisocial personality disorder</li> <li>Prevention of antisocial personality disorder – working with children and young people and their families</li> <li>Assessment and risk management of antisocial personality disorder</li> <li>Treatment and management of antisocial personality disorder and related and co-morbid disorders</li> <li>Psychotherapy and dangerous and severe personality disorder</li> <li>Organisation and planning of services</li> </ul>

Core interventions in the treatment of <b>obsessive-compulsive</b> <b>disorder (OCD) and body dysmorphic disorder (BDD).</b> CG31, 2005 <u>http://www.nice.org.uk/CG31</u>	<ul> <li>Principles of care for all people with OCD or BDD and their families or carers</li> <li>Stepped care for adults, young people and children with OCD or BDD</li> <li>Step 1: awareness and recognition</li> <li>Step 2: recognition and assessment</li> <li>Step 3-5: treatment options for people with OCD or BDD</li> <li>Step 6: intensive treatment and inpatient services for people with OCD or BDD</li> <li>Discharge after recovery</li> </ul>
Dual Diagnosis	
Psychosis with coexisting substance misuse: Assessment and management in adults and young people CG120, 2011 http://www.nice.org.uk/CG120	<ul> <li>recognition, treatment and care of adults and young people with psychosis and coexisting substance misuse in primary care and across mental health and substance misuse services</li> <li>patient access to both age-appropriate mental healthcare and substance misuse services</li> <li>organisation of services including care coordination, joint working arrangements between specialist substance misuse services and CMHT, referral guidelines</li> <li>Inpatient services</li> <li>Involvement and communication of patients and the families</li> </ul>
Drug misuse: psychosocial interventions.	General considerations
CG51, 2007	<ul> <li>Identification and assessment of drug misuse</li> </ul>
http://www.nice.org.uk/CG51	Brief interventions and self-help
	Formal psychosocial interventions
Drug miguage enigid detextification	Residential, prison and inpatient care
Drug misuse: opioid detoxification. CG52, 2007	General considerations
http://www.nice.org.uk/CG52	<ul> <li>Assessment</li> <li>Pharmacological interventions in opioid detoxification</li> </ul>
	<ul> <li>Opioid detoxification in community, residential, inpatient and prison</li> </ul>
	settings
	Specific psychosocial interventions

Relevant SCIE publications	The relationship between dual diagnosis: substance misuse and dealing with mental health issues SCIE Research briefing 30, 2009 Working with families with alcohol, drug and mental health problems
	SCIE Report 2, 2003 <u>Parenting capacity and substance misuse</u> SCIE Research briefing 6, 2004
Autism	
Autism: recognition, referral, diagnosis and management of adults on the autism spectrum CG142, 2012 http://guidance.nice.org.uk/CG142	<ul> <li>The guideline covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of, adults with autism.</li> <li>General principles of care</li> <li>Identification and assessment</li> <li>Identifying the correct interventions and monitoring their use</li> <li>Interventions for autism</li> <li>Interventions for challenging behaviour</li> <li>Interventions for coexisting mental disorders</li> <li>Assessment and interventions for families, partners and carers</li> <li>Organisation and delivery of care</li> </ul>
Autism: Quality Standard QS51, 2014 http://publications.nice.org.uk/autism-gs51	Covers autism in children, young people and adults, including both health and social care services.
Relevant SCIE publications	Improving access to social care for adults with autism Social Care Institute for Excellence, 2011 Mental health and social work SCIE Research briefing 26, 2008 Supporting people in accessing meaningful work: Recovery approaches in community based adult mental health services SCIE Knowledge review 21, 2008

Generalised anxiety disorder and panic disorder (with or without agoraphobia) in adults         CG113, 2011         http://www.nice.org.uk/guidance/CG113         Anxiety disorders: Quality Standard         QS53, 2014. http://publications.nice.org.uk/anxiety-disorders-qs53         Depression: the treatment and management of depression in adults.         CG90, 2009         http://www.nice.org.uk/CG90         Self-harm: the short-term physical and psychological management and secondary prevention of self harm in primary and secondary care         CG16, 2004         http://www.nice.org.uk/CG16	<ul> <li>Care of all people with depression</li> <li>Stepped care</li> <li>Step 1: recognition, assessment and initial management</li> <li>Step 2: recognised depression- persistent subthreshold depressive symptoms or mild to moderate depression</li> <li>Step 3: persistent subthreshold depressive symptoms or mild to moderate depression with inadequate response to initial interventions, and moderate and severe depression</li> <li>Treatment choice based on depression subtypes and personal characteristics</li> <li>Enhanced care for depression</li> <li>Sequencing treatments after initial inadequate response</li> <li>Continuation and relapse prevention</li> <li>Step 4: complex and severe depression</li> <li>Respect, understanding and choice</li> <li>Staff training</li> <li>Activated charcoal</li> <li>Triage</li> <li>Treatment</li> <li>Assessment of needs</li> <li>Assessment of risk</li> <li>Psychological, psychosocial and pharmacological interventions</li> </ul>
<b>Self-harm</b> (longer term management) (CG133) CG133, 2011 <u>http://guidance.nice.org.uk/CG133</u>	
Self harm: Quality Standard QS34, 2014	
http://publications.nice.org.uk/quality-standard-for-selfharm-gs34	

#### Adults with Autism

This NICE Clinical Guideline for the management of adults on the autism spectrum<sup>64</sup> was published in June 2012. It covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of, adults with autism.

The guideline highlights key priorities for commissioners and service providers and emphasizes the need for both health and social care staff to have a good understanding of the condition and the impact that it has on the person's ability to function in both social and physical environments. It also emphasizes the need to understand the impact on and interaction with other coexisting mental and physical disorders and their management.

The guideline suggests and specifies behaviours, which staff and carers should adopt which are sensitive to the needs of adults with autism. This includes communication methods and taking into account the impact of physical environment (e.g. space, noise) in which adults with autism are assessed, supported and cared for, including any factors that may trigger challenging behaviour.

Common issues such as under-reporting and under-recognition of physical disorders in people with autism and the consequences of unusual likes and dislikes about food and/or lack of physical activity is considered. Staff are advised to offer advice about the beneficial effects of a healthy diet and exercise, taking into account any hyper- and/or hypo-sensory sensitivities; if necessary, support referral to a GP or dietician.

Encourage adults with autism to participate in self-help or support groups or access one-toone support, and provide support so that they can attend meetings and engage in the activities.

The management of adults with autism is often complex and NICE recommends that all staff working with adults with autism should work in partnership, offer care and support, and build trusting relationship with adults with autism and, where agreed, with their families, partners or carers.

**Organisation and delivery of care.** Local care pathways should be developed to promote implementation of key principles of good care. There should be a local autism multi-agency strategy group which includes representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector, as well as meaningful representation from people with autism and their families, partners and carers. The aims of the strategy group should include:

- Developing clear policy and protocols for the operation of the pathway.
- Ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway.
- Ensuring that the local care pathway promotes access to services for all adults with autism, including those 'hard to reach' and those from minority groups.
- Making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services.

<sup>&</sup>lt;sup>64</sup> Autism: recognition, referral, diagnosis and management of adults on the autism spectrum CG142, 2012 <u>http://guidance.nice.org.uk/CG142</u>

- Supporting the integrated delivery of services across all care settings.
- Supporting the smooth transition to adult services for young people going through the pathway.
- Auditing and reviewing the performance of the pathway.

This should be augmented in each area with a specialist community-based multidisciplinary team for adults with autism (the specialist autism team) should be established. The specialist autism team should have a key role in the delivery and coordination of:

- Specialist diagnostic and assessment services.
- Specialist care and interventions.
- Advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team).
- Support in accessing, and maintaining contact with, housing, educational and employment services.
- Support to families, partners and carers where appropriate.
- Care and interventions for adults with autism living in specialist residential accommodation.
- Training, support and consultation for staff who care for adults with autism in residential and community settings.

**Identification and assessment**. As part of the process of assessing for possible autism, the guideline advises that assessment of challenging behaviour should be integrated into a comprehensive assessment for adults with autism and that this should include a functional analysis including identifying and evaluating factors that may trigger or maintain the behaviour, such as physical disorders, the social environment, the physical environment, including sensory factors, coexisting mental disorders (including depression, anxiety disorders and psychosis), communication problems and changes to routine or personal circumstances.

Adults with autism should have a:

- Care plan based on the comprehensive assessment.
- 'Health passport' (for example, a laminated card), which includes information for all staff about the person's care and support needs.
- And where necessary a 24-hour crisis management plan, which should detail the likely trigger(s) for a crisis, details about the way in which autism may impact on a person's behaviour leading up to and during a crisis. It should also specify the role of the specialist team and other services (including outreach and out-of-hours services) in responding to a crisis, provide advice to primary care professionals and families, partners and carers about their role in a crisis and detail changes or adaptations to the social or physical environment needed to manage a crisis.

**Interventions for autism**. A range of interventions are described in detail in the guideline. These include:

- Psychosocial interventions for the core symptoms of autism:
  - o a group-based social learning programme focused on improving social interaction
  - an individually delivered social learning programme for people who find groupbased activities difficult.
- Psychosocial interventions focused on life skills, such as:
  - o structured and predictable training programme based on behavioural principles.
  - o a group-based structured leisure activity programme.
  - an individually delivered structured leisure activity programme for people who find group-based activities difficult.
  - o anger management intervention, adjusted to the needs of adults with autism.
  - anti-victimisation interventions based on teaching decision-making and problemsolving skills.
  - o individual supported employment programme.
- Psychosocial interventions for challenging behaviour based on behavioural principles and informed by a functional analysis of behaviour should be offered once direct interventions for triggering or maintaining challenging behaviour have been addressed eg a coexisting mental or physical disorder, or problem related to the physical or social environment.
- Pharmacological interventions for challenging behaviour. Antipsychotic medication for challenging behaviour on its own may be considered when psychosocial or other interventions could not be delivered because of the severity of the challenging behaviour.
- Specific psychosocial interventions for the coexisting mental disorders.
- Specific pharmacological interventions for the coexisting mental disorders.

Biomedical (pharmacological, physical and dietary) interventions are specifically not recommended for managing the core symptoms of autism. These include:

- Anticonvulsants.
- Chelation.
- Exclusion diets (such as gluten or casein-free and ketogenic diets).
- Vitamins, minerals and dietary supplements.
- Drugs specifically designed to improve cognitive functioning.
- Oxytocin.
- Testosterone regulation.
- Hyperbaric oxygen therapy.
- Antipsychotic medication.
- Antidepressant medication.

The NICE guidance recognizes the impact that caring for a family member with autism has on families, partners and carers and recommends that they should be offered an assessment of their own needs. This should include:

- Personal, social and emotional support.
- Support in their caring role, including respite care and emergency plans.
- Advice on and support in obtaining practical support.
- Planning of future care for the person with autism.

When the needs of families, partners and carers have been identified, the local service should provide information about, and facilitate contact with, a range of support groups including those specifically designed to address the needs of families, partners and carers of people with autism.

**Improving access to care** is a key recommendation in the guideline. It advises that there should be:

- A single point of referral (including self-referral) to specialist services for adults with autism and that in order to support access to services and increase the uptake of interventions.
- Systems (for example, care coordination or case management) should be in place to provide for the overall coordination and continuity of care for adults with autism. Additionally the guideline recommends.
- "Designating a professional to oversee the whole period of care (usually a member of the primary healthcare team for those not in the care of a specialist autism team or mental health or learning disability service)".

# The quality standard for Autism<sup>65</sup> (QS51) published by NICE in January 2014 for Autism applies to services for children, young people and adult with Autism.

Statement 1. People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

Statement 2. People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

Statement 3. People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

Statement 4. People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Statement 5. People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.

<sup>&</sup>lt;sup>65</sup> Autism: Quality Standard QS51, 2014 <u>http://publications.nice.org.uk/autism-qs51</u>

Statement 6. People with autism are not prescribed medication to address the core features of autism.

Statement 7. People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Statement 8. People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

#### Personality disorders:

There are two NICE guidelines published for personality disorder. No quality standards currently exist for the treatment, management or prevention of personality disorder.

The guideline on **antisocial personality disorder (ASPD)**<sup>66</sup> was recently modified in September 2013. It makes recommendations for the treatment, management and prevention of antisocial personality disorder (ASPD) in primary, secondary and forensic healthcare. It includes recommendations for a wide range of services for adults with ASC including those provided within mental health (including substance misuse) services, social care and the criminal justice system.

Under current diagnostic systems, antisocial personality disorder is not formally diagnosed before the age of 18 but the features of the disorder can manifest earlier as conduct disorder. The course of antisocial personality disorder is variable and although recovery is attainable over time, some people may continue to experience social and interpersonal difficulties. Antisocial personality disorder is often comorbid with depression, anxiety, and alcohol and drug misuse.

The guideline recognizes the important role that families or carers play in both the prevention and the treatment of antisocial personality disorder.

The NICE guideline recommends key priorities for implementation. These are:

- An optimistic and trusting relationship, which is consistent and reliable, should be developed between staff and people with ASPD, focusing on attainable recovery.
- Assessment in forensic/specialist personality disorder services. Healthcare professionals in forensic or specialist personality disorder services should consider, as part of a structured clinical assessment, routinely using:
  - $\circ$   $\,$  a standardised measure of the severity of antisocial personality disorder  $\,$
  - a formal assessment tool such as Historical, Clinical, Risk Management-20 (HCR-20) to develop a risk management strategy.
- **Treatment of comorbid disorders**. People with antisocial personality disorder should be offered treatment for any comorbid disorders. This should happen regardless of whether the person is receiving treatment for antisocial personality disorder.

<sup>&</sup>lt;sup>66</sup> Antisocial personality disorder: treatment, management and prevention. NICE CG77, 2009/2013 <u>http://www.nice.org.uk/CG77</u>

- Psychological interventions. For people with antisocial personality disorder with a
  history of offending behaviour who are in community and institutional care, consider
  offering group-based cognitive and behavioural interventions (for example,
  programmes such as 'reasoning and rehabilitation') focused on reducing offending and
  other antisocial behaviour.
- **Multi-agency care**. Provision of services for people with antisocial personality disorder often involves significant inter-agency working. Therefore, services should ensure that there are clear pathways for people with antisocial personality disorder so that the most effective multi-agency care is provided. These pathways should:
  - o specify the various interventions that are available at each point
  - enable effective communication among clinicians and organisations. Clearly agreed local criteria should also be established to facilitate the transfer of people with antisocial personality disorder between services.
- Services should consider establishing antisocial personality disorder networks, where possible linked to other personality disorder networks. These networks should:
  - take a significant role in training staff, including those in primary care, general, secondary and forensic mental health services, and in the criminal justice system
  - o have resources to provide specialist support and supervision for staff
  - take a central role in the development of standards for and the coordination of clinical pathways
  - o monitor the effective operation of clinical pathways.

The second clinical guideline for personality disorder is concerned with the treatment and management of **borderline personality disorder**<sup>67</sup> (CG78).

Borderline personality disorder (BPD) is characterised by significant instability of interpersonal relationships, self-image and mood, and impulsive behaviour. There is a pattern of sometimes rapid fluctuation from periods of confidence to despair, with fear of abandonment and rejection, and a strong tendency towards suicidal thinking and self-harm. Transient psychotic symptoms, including brief delusions and hallucinations, may also be present. It is also associated with substantial impairment of social, psychological and occupational functioning and quality of life. People with borderline personality disorder are particularly at risk of suicide.

The guideline highlights the fact that borderline personality disorder is often comorbid with depression, anxiety, eating disorders, post-traumatic stress disorder, alcohol and drug misuse, and bipolar disorder and importantly recognizes that people with borderline personality disorder have sometimes been excluded from any health or social care services because of their diagnosis.

Key priorities for implementation identified in the guideline are aimed at improving:

• Access to services. People with borderline personality disorder should not be excluded from any health or social care service because of their diagnosis or because they have self-harmed.

<sup>&</sup>lt;sup>67</sup> Borderline personality disorder: treatment and management.NICE CG78, 2009 <u>http://www.nice.org.uk/CG78</u>

- Autonomy and choice. Services should work in partnership with people with borderline personality disorder to develop their autonomy and promote choice by ensuring they are actively involved in finding solutions to their problems, including during crises and encouraging them to consider the different treatment options and life choices available to them, and the consequences of the choices they make.
- The relationship between staff and the person with borderline personality disorder in order to maximize the possibility of recovery and overcome previous negative experiences that people with BPD may have had with services.
- Managing endings and supporting transitions. Anticipate that withdrawal and ending of treatments or services, and transition from one service to another, may evoke strong emotions and reactions in people with borderline personality disorder.
- Assessment. Community mental health services should be responsible for the routine assessment, treatment and management of people with borderline personality disorder.
- **Care planning**. Teams working with people with borderline personality disorder should 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 include 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.
- **Psychological treatment** should be provided in line with the clinical guideline.
- **Drug treatment** should not be used specifically for borderline personality disorder or for the individual symptoms or behaviour associated with the disorder (for example, repeated self-harm, marked emotional instability, risk-taking behaviour and transient psychotic symptoms).

The role of specialist personality disorder services within trusts is described in detail in the full guideline. It advocates development of multidisciplinary specialist teams and/or services for people with personality disorders. These teams should:

- Provide assessment and treatment services for people with borderline personality disorder who have particularly complex needs and/or high levels of risk.
- Provide consultation and advice to primary and secondary care services.
- Offer a diagnostic service when general psychiatric services are in doubt about the diagnosis and/or management of borderline personality disorder.
- Develop systems of communication and protocols for information sharing among different services, including those in forensic settings, and collaborate with all relevant agencies within the local community including health, mental health and social services, the criminal justice system, CAMHS and relevant voluntary services.
- Be able to provide and/or advise on social and psychological interventions, including access to peer support, and advise on the safe use of drug treatment in crises and for comorbidities and insomnia.
- Work with CAMHS to develop local protocols to govern arrangements for the transition of young people from CAMHS to adult services.
- Oversee the implementation of this guideline.

- Develop and provide training programmes on the diagnosis and management of borderline personality disorder.
- Monitor the provision of services for minority ethnic groups to ensure equality of service delivery.

# 7. Evidence review

## 7.1 Primary prevention for mental health

We conducted a literature review to explore the evidence base for primary prevention or early interventions for mental health in adults with personality disorder, dual diagnosis or autism and older people. We have not considered secondary interventions or treatments for people who are already known to have a mental illness. This was not a systematic review seeking to identify and assess all the studies that have been published in this area, rather a search for high-level evidence from systematic reviews, meta-analyses and health economic studies that could be used to inform the delivery and targeting of interventions to groups at higher risk of mental ill-health in Cambridgeshire. Full details of the search strategy are given in the appendix.

Generally the authors of the systematic reviews felt that the quality of the published studies in this area varied considerably. Some good quality randomized controlled studies were identified in some areas, but many studies were lower quality observational studies. Common weaknesses of studies included a small number of participants, short duration of interventions, short follow-up periods and poor reporting of interventions or outcomes. In many cases weaknesses in the evidence base limited the strength of the conclusions that the systematic review authors were able to make about the effectiveness of different interventions.

In the tables we have summarized the literature relating to the effectiveness of interventions for adults and older people separately. The focus of the different systematic review varied, with some focusing on interventions based in a particular setting, for example the workplace, for any mental health issues, and other reviews focusing on a specific interventions to prevent a particular mental health condition. Further details of the key reviews identified are presented as a series of tables in the appendix.

## 7.2 Interventions in work settings

The authors of a general review comparing the effectiveness and costs of two or more interventions to promote mental health and wellbeing and/ or prevent the onset of mental health problems across all age groups concluded that one area where there was a strong case for action and investment for adults was workplace interventions eg health promotion and stress management programmes (McDaid & Park 2011- see Table 50). A systematic review on the prevention of mental health issues in organizations found some evidence for improvements for workers across a range of outcomes including sickness absence, job control and performance, mental health scores and work life balance (Corbière et al 2009 – see Table 51). The review included a range of interventions but did not draw any conclusions about which interventions were likely to be the most effective.

### 7.3 Interventions targeting particular mental health issues

### Suicide (Table 52)

Evidence shows that BPD patients are at high risk for completed suicide<sup>686970</sup>. It is the only personality disorder to have suicidal or self-injurious behaviour among its diagnostic criteria<sup>71</sup>. A prospective study showed a 3.8% completed suicide rate in a sample of borderline patients at six-year follow-up<sup>72</sup>. Earlier studies reported rates from 8% to 10%—approximately 50 times greater than the general population<sup>73</sup>.

We found that a review of community campaigns to reduce suicide rates found that long-term campaigns operating at multiple levels and had succeeded in establishing a community support network could have a positive impact on suicide rates. The same review found that other programmes that had improved knowledge and attitudes seemed to show a benefit at a theoretical-intellectual level rather than having an impact on actions, and very short interventions did not seem to have any effect<sup>74</sup>). A review of screening primary care populations for suicide risk<sup>75</sup> concluded that there are tools that may be able to detect at-risk adults, although their performance was lower for older adults. This review also concluded that psychotherapy can reduce suicide attempts and depression in high-risk adults (usually those with a history of suicide attempts).

<sup>&</sup>lt;sup>68</sup> American Psychiatric Association. Practice guideline for the treatment of patients with borderline personality disorder.Am J Psychiatry. 2001;158(suppl 10):1-52.

 <sup>&</sup>lt;sup>69</sup> Zanarini MC, Frankenburg FR, Hennen J, et al. The McLean study of adult development: overview and implications of the fi rst six years of prospective follow-up. J Personal Disord.2005;19(5):505-523.

<sup>&</sup>lt;sup>70</sup> Paris J. Chronic suicidality among patients with borderline personality disorder. Psychiatr Serv. 2002;53(6):738-742.

<sup>&</sup>lt;sup>71</sup> Zanarini MC, Frankenburg FR, Hennen J, et al. The McLean study of adult development: overview and implications of the fi rst six years of prospective follow-up. J Personal Disord.2005;19(5):505-523.

<sup>&</sup>lt;sup>72</sup> Zanarini MC, Frankenburg FR, Hennen J, et al. The McLean study of adult development: overview and implications of the first six years of prospective follow-up. J Personal Disord.2005;19(5):505-523.

<sup>&</sup>lt;sup>73</sup> American Psychiatric Association. Practice guideline for the treatment of patients with borderline personality disorder.Am J Psychiatry. 2001;158(suppl 10):1-52.

Fountoulakis KN. Gonda X. Rihmer Z. Suicide prevention programs through community intervention. Journal of Affective Disorders 2011, 130(1-2): 10-16

<sup>&</sup>lt;sup>75</sup> O'Connor E. Gaynes BN. Burda BU. Soh C. Whitlock EP. Screening for and treatment of suicide risk relevant to primary care: a systematic review for the U.S. Preventative Services Task Force. Annals of Internal Medicine 2013, 158: 741-754

# **General review papers**

# Table 50: Primary prevention in mental health: interventions across all populations

Study and Aim:	Population	Interventions	Key findings	Author's conclusions
McDaid & Park 2011; systematic review of 47 studies comparing the effectiveness and costs of two or more health-focused interventions to promote mental health and wellbeing and/or prevent the onset of mental health problems.	All age groups	The review focused on early years and parenting interventions, actions set in school and workplaces and measures targeted at older people	<ul> <li>Areas where the authors felt there was a strong case for action and investment included:</li> <li>Childhood and targeted at mothers eg health visiting and parenting programmes</li> <li>Workplace interventions eg health promotion and stress management programmes</li> <li>Group and home visiting activities for older people eg group-based exercise and psychosocial interventions</li> </ul>	The case for investment in parenting and health visitor-related programmes was most strong. Benefit was also observed in workplace interventions and for group and home visiting activities for older people.

# Table 51: Primary prevention for mental health: interventions for adults in work settings

Study and Aim:	Population	Intervention	Key findings	Author's conclusions
Corbière et al 2009; systematic review of 24 studies on the <b>prevention of mental</b> <b>health issues in</b> <b>organizations</b> (8 primary prevention studies, 14 secondary prevention studies and 2 mixed studies).	For the primary prevention studies: Adult employees (n=4,627) and managers (n=148)	Interventions included psychosocial training, cognitive behavioural intervention, participatory organizational intervention, managerial improvement programmes, relaxation techniques, exercise and stress management	Outcomes of primary prevention studies assessed varied between studies. Areas where a significant improvement was seen following the intervention included: • Sickness absence • Job control / authority over decisions • Mental health scores • Balance between effort and reward • Self-performance ratings • Work-life balance	More interventions focusing on secondary prevention than primary prevention were identified. The results were promising in terms of positive improvements for workers, but there were inconsistencies in study design and outcome measures.

Study and Aim:	Population	Intervention	Key findings	Author's conclusions
Fountoulakis et al 2011; systematic review of 14 studies on community campaigns to reduce suicide rates	All ages	Community campaigns to reduce suicide rates	<ul> <li>The only reductions in suicide rates were seen in long-term programmes that used society commitment at multiple levels and succeeded in establishing a community support network.</li> <li>The success of most programmes in improving knowledge and attitudes seems to be at a theoretical-intellectual level rather than having any impact on actions.</li> <li>Very short interventions did not seem to have any effect</li> </ul>	Although community education programmes for suicide prevention are common, reporting on their efficacy is limited.
O'Connor et al 2013; systematic review of screening for suicide risk	Primary care population (all ages)	Screening for suicide risk in primary care settings	<ul> <li>Minimal evidence that screening tools can identify some adults at increased risk for suicide in primary care. Performance was lower for older adults and high-risk adolescents.</li> <li>Some evidence that psychotherapy reduced suicide attempts in high-risk adults<sup>76</sup> (by an estimated average of 32%), but not adolescents.</li> <li>Psychotherapy also had small beneficial effects on depression for adults and adolescents</li> </ul>	Some evidence that screening tools could identify adults at increased risk of suicide, but it is unclear whether the benefits of psychotherapy would also apply to a screen detected population.

# Table 52: Primary prevention in mental health: interventions for adults targeting particular mental health issues

<sup>&</sup>lt;sup>76</sup> These adults usually had a history of multiple suicide attempts

Study and Aim:	Population	Intervention	Key findings	Author's conclusions
Mammen & Faulkner 2013; systematic review of 30 prospective studies of <b>physical</b> activity for the prevention of depression	People who were not depressed at baseline 26 of 30 studies had more than 1,000 participants (11 had more 5,000 participants)	Aerobic physical activity assessed in a prospective, longitudinal study. Follow-up periods ranged from 1 to 27 years.	<ul> <li>25 of 30 moderate to high quality studies found that physical activity was associated with lower rates of depression. The other five studies did not find a relationship between physical activity and depression</li> <li>4 studies concluded that the protective effect of physical activity may be specific to women</li> <li>Positive effects were seen for varying levels of physical activity. It was not clear if higher levels of activity are associated with decreased risk of depression due to heterogeneity in the way that physical activity was measured.</li> <li>6 studies looking at fluctuating levels of physical activity found that reducing activity over time increases the risk of depression relative to remaining active or increasing activity levels and that increasing activity lowers the risk</li> </ul>	There was sufficient evidence to conclude that physical activity may prevent depression. Promoting any level of physical activity could be an important strategy for the prevention of future depression.

CBT = cognitive behavioural therapy; ES = effect size; OR = odds ratio; PTSD = post-traumatic stress disorder; RCT = randomized controlled trial; RR = relative risk; SMD = standardized mean difference

# 7.4 Early interventions to reduce dependence upon specialist mental health services and promote independent living in the community

This section describes evidence about interventions which could prevent, or slow progression of, the mental health problems of interest in this report.

One of the aims of this report is to identify and review opportunities for commissioners and providers to prevent these mental health problems, and to intervene early to alter their course. We need services that are sustainable and keep patients as well as possible for as long as possible, without the need for specialist mental health services

We conducted a literature search to identify high quality evidence of effective early interventions in peer-reviewed journals published subsequent to the relevant NICE guideline publications. We excluded studies which examined specific clinical types of treatment for instance: pharmacological therapy, nutritional supplements, psychological therapies as these have been included in the NICE publications in the form of either guidelines or technology appraisal guidance.

The remaining papers were few. Many were small case series of insufficient quality, and did not evaluate or find interventions which were effective at reducing demand on specialist mental health services.

We then widened our search for effective early intervention service delivery models. We searched for reviews from the Cochrane Library as well as grey literature publications such as The Kings Fund, The Mental Health Foundation, Centre for Mental Health, MIND and ReThink for publications published subsequent to the NICE guidelines.

Most of the service delivery interventions that we found identified have not been evaluated and published in a peer review journal. They are simply case studies of initiatives elsewhere in the UK with only high-level, descriptive information and published on the website. Some of these case studies state that they are effective, but the evaluation was not reported. A few case studies have been evaluated and in some cases these evaluation reports provide moderate evidence that the model may be effective. The review of integrated care models undertaken in November 2013<sup>77</sup> was a useful start in trying to identify alternative service delivery models, and is the basis of this updated review. We have excluded any studies found which concluded that the intervention/initiative was ineffective, or where the intervention could not be shown to be clinically effective.

We found no new health economic studies about the cost effectiveness of the alternative models of service delivery.

A number of the reports do not refer directly and specifically to the patient groups that this JSNA is concerned with but we have included them where there is a strong likelihood that the intervention is relevant.

The Kings Fund<sup>78</sup> published a report in October 2013 which identified the key components from five UK programmes delivering co-ordinated care for people with long-term and complex needs. Although none of the case studies were for adults with autism, personality disorder or dual diagnosis and some were specifically for older people, there were a number of conclusions which are relevant to the delivery of care for people with multiple health and social care needs, who often receive a very fragmented service, resulting in less than

<sup>&</sup>lt;sup>77</sup> Author: Katharine Hartley, SpR Public Health. November 2013

<sup>&</sup>lt;sup>78</sup> Nick Goodwin, Lara Sonola, Veronika Thiel (2013) Co-ordinated care for people with complex chronic conditions: Key lessons and markers for success. The Kings Fund

optimal care experiences, outcomes and costs; the report called for improvements to care coordination.

The King's Fund report had a number of conclusions:

- a holistic focus is needed to support patients and carers to become more functional, independent and resilient
- communities must be aware of and trust in care co-ordination programmes
- effective communication is critical for developing good working relationships between members of the multidisciplinary team.
- care co-ordination programmes should be localised so that they address the priorities of specific communities.
- leadership and commitment (from commissioners and providers alike) is vital to establish a shared vision and challenge silo-based working.

Across the five sites common challenges included:

- funding
- lack of GP engagement
- a lack of integrated IT systems
- problems caring for people in remote and rural locations.

Important policy points based upon learning from all five pilots were that:

- care co-ordination innovations can take some years to mature and to build legitimacy and acceptance.
- successful approaches are very context-specific; care models cannot be transported 'en bloc' from one setting to another.
- care co-ordination should primarily be a quality improvement strategy rather than one aimed at reducing costs.
- models of care co-ordination are likely to be more effective when operating as 'fully integrated' provider teams with some operational autonomy.

Intervention (all evidence is weak unless specifically	Impact
highlighted as otherwise) The Esteem Team: Co-ordinated care in the Sandwell Integrated Primary Care Mental Health and Wellbeing Service <sup>79</sup>	No information about cost effectiveness available
The aim of the Esteem Team is to support people with mild to moderate mental health conditions and complex social needs, at an early stage to prevent deterioration and admission to secondary care services. In this model, Link workers act as patients' navigators through the health and social care system and typically have a social worker background and/or personal experience with mental health conditions. The Esteem Team can refer patients to a wide variety of statutory and voluntary sector services including social services, debt advice agencies, substance abuse counselling, therapeutic services and peer support groups. They also visit patients at home and accompany them to appointments if required. The service is not time limited.	
Other studies identified:	
<ul> <li>Chronically Excluded Adults Project<sup>80</sup>.</li> <li>The CEA service in Cambridgeshire works with the most chaotic and excluded adults in the county to improve outcomes for individuals and for society as a whole. It targets clients who have fallen between services in the past and employs a coordinator who uses a person centred approach to tailor a support package around each client's needs.</li> <li>Clients' service use was measured 12 months prior to them entering the project, and found that of the fifteen entering the pilot (15) in the first year 46% had had a professional mental health intervention, and 43% had self-reported mental health issues. 75% had had a criminal justice intervention, and 43% had been in prison. All were homeless.</li> <li>A full evaluation of the CEA service was conducted as part of the MEAM pilots, which looked at the effect the service had on clients' wellbeing and their use of wider services.</li> </ul>	<ul> <li>This has shown significant wellbeing improvements for clients across three quantitative measures.</li> <li>The evaluation also observed important changes in clients' service use and the associated costs. During its first year CEA service led to a 7.8% reduction in client's costs to services particularly the criminal justice system, with clients less frequently cautioned, arrested, required to attend court, or spend time in police custody or prison.</li> <li>While the costs of providing housing, medical treatment and help with substance misuse increased over the first year these were offset by savings to the criminal justice system. In year two these savings are increased. The overall cost reduction compared to baseline was 26.4% (£958 per client per month) in Cambridgeshire.</li> <li>The pilot was small (n=13) Results were not replicated to the same extent at other pilot sites (Derby and Somerset)</li> </ul>

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http://www.kingsfund.org.uk/publications/esteem-team
 Battrick T, Crook L, Edwards K, Moselle B (2014) Evaluation of the MEAM pilots – Update on our findings. Report supplied by CCC PH Department.

<b>The Leeds Survivor Led Crisis Service</b> <sup>81</sup> offers services to people experiencing mental health crisis. The service provides an evening helpline 365 days a year and a crisis house, open Friday to Monday, 6pm to 2am, for anyone in crisis. It is run by people who have experienced mental health problems. It provides an alternative to hospital at times of immediate crisis, support individuals to develop their own strategies for crisis prevention and management and to address isolation and its associated problems, and provides a place where visitors can utilise their own experience to assist themselves and others through the sharing of problems, alternatives and solutions.	<ul> <li>The 2012 evaluation report<sup>83</sup> was too small to be able to draw conclusions about either the effectiveness or the cost effectiveness of the service.</li> <li>The sample size too small</li> <li>only included patients who self-harmed and were regular attendees at A&amp;E.</li> </ul>
<ul> <li>and unpaid costs.</li> <li>Suicidal Crisis, Maytree, London<sup>84</sup>.</li> <li>The aim of Maytree is to help people in suicidal crisis to reengage with life and to restore hope through considering options and developing resilience.</li> <li>The approach is to provide people in the midst of a suicidal crisis with the opportunity for a few days rest and reflection in a calm, safe and relaxed environment. It is a small project but can support four "guests" at a time. The service runs 24 hours a day, 365 days a year. The staff team spend up to 77 hours with each guest over their stay, giving them the opportunity to talk through their fears and concerns.</li> <li>In 2012, researchers from the University of East London and the Tavistock Clinic published a study about the impact of the Maytree service. It found that a majority of guests reported reduced suicidal levels during the stay, and the sample interviewed 4-9 months after the stay reported similarly, that they were less suicidal. For a small proportion of guests no reduction in suicidal levels was reported.</li> </ul>	Patients felt less suicidal whilst at Maytree and for several months afterwards. Evaluation included>50 consecutive patients.

<sup>81</sup> 

http://www.lslcs.org.uk/what-do-we-do/our-therapeutic-approach LSLCS- a Social Return on Investment Analysis http://www.lslcs.org.uk/wp-content/uploads/Summary-report-82

final\_May12.pdf Beckett J, D'Angelo G, Pattison L & Walker T. Leeds Survivor Led Crisis Service <u>Self Harm Evaluation</u> 83 Project 2012

Briggs S, Linford H, Harvey A. Guests experiences of Maytree during and after their stay 2012. http://www.maytree.org.uk 84

Autism: Brokerage <sup>85</sup>	No outcomos reported			
The National Autistic Society (NAS) offer 'brokerage' support	No outcomes reported			
to clients to help them plan the things they want and need to				
do in their lives. They support people and their families who				
want extra assistance to plan, to make choices and to help				
them access support that they need or desire.				
The NAS describe the role of the broker as someone whose				
role it is to identify with the person/family				
<ul> <li>who and what is important in their lives</li> </ul>				
<ul> <li>what is and what is not working in their life</li> </ul>				
<ul> <li>what they would like to change or achieve</li> </ul>				
<ul> <li>the support that they have</li> </ul>				
<ul> <li>how they will stay well, healthy and safe</li> </ul>				
<ul> <li>how they will stay in control of their life.</li> </ul>				
People who access this service either as part of LA funding,				
their own personal care budget or through self funding.				
Brokerage pilots are currently available in Manchester,				
Newcastle, Plymouth and Leicester/Northampton.				
Welfare advice for people who use mental health services,	Limited detail on outcomes but the			
Sheffield <sup>86</sup> .	cost benefit hypothesis is plausible			
The Centre for Mental Health report finds that specialist	albeit with no economic study.			
welfare advice for people using secondary mental health				
services can be very good value for money. It concludes that	City based so may not transfer to			
specialist welfare advice can cut the cost of healthcare in three	city/rural setting			
main ways:				
1. reductions in inpatient lengths of stay through				
resolving complex housing problems such as possible				
eviction or repossession and enabling a patient to be				
discharged from hospital more quickly.				
2. prevention of homelessness: for example if they				
prevent this by negotiating directly with landlords and				
creditors in cases of rent arrears.				
3. prevention of relapse: welfare advice service can help				
to reduce the risk of relapse, most obviously by				
directly acting on an immediate cause of acute stress				
which threatens to trigger relapse, but also by				
reducing the vulnerability of clients to future problems				
through the development of improved coping				
mechanisms.				
The Sheffield Mental Health Citizens Advice Bureau is one of				
only two services in the country specifically dedicated to the advice needs of people with severe mental illness. The				
average cost of its advice is around £260 per client. Just under				
half of these seen are inpatients, with the remainder living in				
community settings. The service focuses on complex welfare				
problems involving legal or other issues that are beyond the				
capacity or expertise of staff working in mental health services				
to resolve.				
The service supported 622 clients presenting with 1,725				
issues, 64% of clients required case work, with most of the remainder being given advice or information. 48% of clients				

http://www.autism.org.uk/our-services/brokerage.asp
 http://www.centreformentalhealth.org.uk/pdfs/Welfare\_advice\_summary.pdf

were inpatients and the majority of the remainder were clients in receipt of statutory mental health services. 21% of clients were homeless.	
Dual Diagnosis: Reducing reoffending among the mentally ill with drug and alcohol problems. Manchester Offenders: Diversion Engagement Liaison service (Mo:Del). The objective of the project is to reduce criminal activity, drug and alcohol use, improve mental and physical health and increase engagement with services. amongst people with a history of offending, current substance misuse and probable diagnosis of mental illness or personality disorder)by helping them engage with mental health and substance misuse services.	Reduced reoffending (27% vs 67%), drink and drug use and mental health problems.
There are approximately 700 service users per year, supported by a team of 11wte including one social worker, one probation officer, four nurses and a consultant nurse. Approximately half of MO:DEL clients are "case managed" by the team because their care is not being managed elsewhere. MO:DEL works with them for up to six months, providing psychological interventions such as cognitive behavioural therapy, and providing intensive case management working to re-engage them with relevant services.	
The scheme also provides training to criminal justice staff to help them identify people with a mental health problem who could be diverted to the service. If offences are more serious, offenders go before a "targeted services court", a specialist court where the magistrates are trained in mental health and can consider MO:DEL recommendations.	
<b>Anti-Social Behaviour and Mental Health, London.</b> The jointly commissioned London Councils', report <sup>87</sup> concluded that closer working relationships between social care, health services, police and community safety teams could help to identify individuals involved in anti-social behaviour who have mental health issues and provide them with appropriate care, increased awareness among frontline community safety staff would make them better placed to identify early signs of mental illness and that the development of a common approach between professions could help secure better outcomes for individuals in need. The report highlighted the work of the London Boroughs of Ealing and Southwark as examples of good practice.	No quantitative information available about the impact of these schemes actual reduction of ASB (no quantitative outcomes reported) on service utilisation, and no information about the cost effectiveness of either scheme highlighted.
In Ealing, the council has created 'community contact reports' that draw together information about those involved in anti- social behaviour from a range of services, including social care and the police, to provide a fuller picture of the individual's situation and the nature and degree of their illness. This says the report, has helped mental health professionals challenge patients who present a distorted picture of their lives, informed	

<sup>&</sup>lt;sup>87</sup> <u>Anti-Social Behaviour and Mental Health</u> <u>http://www.londoncouncils.gov.uk/policylobbying/crime/publications/asbmentalhealth.htm</u>

<ul> <li>the development of care plans and allowed services to access funding to provide supported accommodation and support packages to individuals.</li> <li>In Southwark the council's anti-social behaviour unit works with the South London and Maudsley NHS Foundation Trust to share information about individuals and use hospital discharge and care plans as a means of minimising repeat anti-social behaviour.</li> </ul>	
Nottinghamshire Asperger Syndrome Team The national Autism Society highlight a scheme in Nottinghamshire between NHS trust and Nottinghamshire adult social care departments where they have established specialist teams to support adults with autism.	No outcomes information available.
The health team includes a clinical psychologist, occupational therapist and speech and language therapist. It focuses on multi-disciplinary diagnostic assessment and post-diagnostic support. The social care team, made up of five social care staff, provides specialist assessment, care management and short-term interventions. The team also provides social and emotional support and assistance with employment and accommodation. The team offers community care assessments by assessors who have a good understanding of autism. In addition, the dedicated team can help people plan how best to get support via the personal budget, find self-help groups for people with Asperger's Syndrome and their families and they can put them in touch with groups which offer opportunities for skill development or physical activity.	

As well as seeking new ways of delivering services with the aim of achieving effective health outcomes, within the resources available, the process of service transformation needs to be taken into consideration. A recently published report<sup>88</sup> reviewed the transformation of mental health services in England and its relevance to the current policy of community-based care as a replacement for acute and long-term care provided in large institutions. They noted that this model of care from hospital to community-based alternatives is also a long-standing policy objective for physical healthcare in the United Kingdom, but that the model of community based care for mental health and for physical health has not been compared.

Amongst the conclusions, the authors pointed out that transformation of mental health services was not an easy, consistent or linear process. In addition, moving the location of care without redesigning is not enough – existing services and institutionalised approaches should not simply be replicated in new settings, nor can successful models from elsewhere be easily adopted in new areas without local redesign. They recommend that the choice of particular care models should be driven by local need, and supported by national mechanisms/policies.

<sup>&</sup>lt;sup>88</sup> <u>Helen Gilburt, Edward Peck, Beccy Ashton, Nigel Edwards, Chris Naylor</u> (2014) Service transformation. <u>http://www.kingsfund.org.uk/sites/files/kf/field/field\_publication\_file/service-transformation-lessons-mental-health-4-feb-2014.pdf reviewed</u>

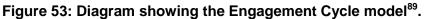
# 8. Stakeholder engagement

This section describes the results of engagement with stakeholders in mental health services for adults with autism, personality disorder and dual diagnosis.

The engagement cycle (Figure 53) was developed on behalf of the Department of Health in 2009. It was based on work carried out with Croydon PCT and developed and tested with national stakeholders and five additional PCTs. The engagement cycle offers a way of approaching Patient and Public Engagement in planning and commissioning and highlights the role of stakeholder engagement at different stages of the commissioning cycle.

The JSNA is part of analysing and planning services. In accordance with the engagement cycle model, part of the process of developing the JSNA is to identify needs and aspirations of the relevant patient or client groups, by asking those familiar with using or delivering those services. The qualitative information gathered is an important additional source of information for triangulation with quantitative data about need and activity, and information about commissioned services.





Our approach to eliciting qualitative information to inform this adult JSNA was to engage with steering group members and service providers, as well as service users (SUs) including people with the relevant mental health disorders and/or their carers. We:

- 1. Conducted workshop sessions with steering group members in order to gain a better understanding of what their perception was of the services that are commissioned and the key problem areas that they consider needed to be addressed.
- 2. Invited written feedback from steering group members and relevant colleagues about their services, the key issues and how they might be resolved
- Listened to a range of service users, their carers or their representatives about their experiences of accessing and using mental health or support services in Cambridgeshire, and their views on what support they needed in order to help them live

<sup>&</sup>lt;sup>89</sup> www.engagementcycle.org

as well as they could. In practice, we conducted a number of one to one telephone interviews with service users/carers and held one all day meeting in Cambridge as four out of the five workshop days had only very low numbers of registered participants.

#### 8.1 Conversations with service users, carers and other stakeholders

In January and February 2014, we arranged five service user events, in Wisbech, Huntingdon and Cambridge. Four of these events were cancelled due to very low response rates, but those people who had expressed an interest in events were asked if they would take part in a telephone interview instead. All those invited agreed to be telephoned by Solutions for Public Health. The telephone interviews were approximately 45 minutes long.

The aim of both the telephone interviews and the meetings with service users/carers was to find out from a service user perspective

- What services they used and found helpful.
- The key challenges that they faced.
- What suggestions they had for improving services in a way that would have a positive impact on their (or their relative's) wellbeing.

In total, we spoke to 24 carers or service users of both adult and older people's mental health services, some of whom were also providing support for mentally ill adults or older people through voluntary or paid work. None worked for a statutory funded agency. Only eight of the 24, were concerned with older peoples mental health services only.

In addition, we conducted workshop sessions with the Joint Mental Health JSNA steering group whose remit included both adult and older people mental health issues. The membership was made up of 26 people including clinical, housing, public health, statutory commissioner, third sector agencies and provider representatives. In addition we sought input from the Chief Executive of the Police and Crime Commissioners office in Cambridgeshire.

**Common Themes.** There were a number of common themes that were identified by service users, carers and by steering group members and staff involved in providing services. Given the limited response rates and the qualitative nature of all of the information received, we only identified themes that had been raised by both the steering group members and the service users Some of these were common to both older people and to adults with mental ill health. They included issues relating to:

- Service delivery
- Organisational challenges
- Coordination of services
- Safeguarding of vulnerable people
- Access to services
- Transition between services
- Continuity of relationships
- Culture and equity
- Physical health and mental health
- Carers needs

#### Service delivery

A number of service users commented on the **complexity of the services that they interface with**, and the fact that they sometimes seem fragmented "even when within the NHS", with different organisations or teams being involved. These might include the GP, housing officer, community health team, specialist mental health professionals, social services, the police and support from third sector organisations. There was agreement that caring for people with mental health is demanding upon family, friends and professionals alike but "there are a lot of different people involved over time and everyone knows different things, but often they have no idea if information is being acting on outside of their own team or organisation". Some clients who receive health or personal care at home either for their mental health condition or for physical health needs, said that they found that uncertainty and change was a contributing factor in how well they felt. Not knowing when to expect a home carer or having lots of different carers with whom they were unfamiliar caused them to feel more confused and anxious. Both users and staff commented, "Services on the ground would sometimes benefit from **better coordination and cooperation between organisations and teams**."

*Safeguarding* of both adults and older people was raised as an important multi-agency issue, both in the context of keeping the patient or client safe, but also because occasionally the carers were vulnerable as well and they need help and support. The complexity of different service providers and commissioners was raised as being a challenge.

#### Access to services

Some SUs reported that they 'fell between' different parts of the NHS and could not get treatment or support, as they 'didn't fit into the right box' or have one clear 'label'. This was because they had more than one mental health condition, had both mental and **physical ill-health** or straddled the mental health services for adults and older people. SUs felt that there needed more flexibility and sensitivity in deciding which services should be available for people with mental illness who were older. For example, in cases where patients felt isolated and lonely and that this contributed to their mental illness, for instance depression, the view was that they should have access to local, community support and advice which is available for older people, even if they were under 65 years old. In other instances, especially where patients had other functional mental illness which they had already been diagnosed with during adulthood, it was thought that **the transition to older people's mental health services was artificial** and that continuity of care would be more important than simply their age. One client told us that "Services are mainly historical: surely they need to be configured around the needs of the patients who use them, not around the organisations who deliver them".

Other factors which mattered to older people included the constraints of **public transport** or **caring/working commitments impacting on their abilities to access** mental health support. If support is difficult to access because of the time of day or because of where it is located, then SUs felt that they were disadvantaged. This was an important factor for people living in rural areas in particular.

#### Continuity of relationships, variation and informed choice

Service users told us that they had a variable experience of services, but that in general, they needed mental health services to be **accessible and consistent.** 

Some people told us that their GPs were keen to refer them to talking therapies, whilst others were not offered the opportunity for referral to IAPT services, rather they were given a prescription. In both of these instances, the SUs told us that they got better.

It was also apparent that for those older people who were offered talking therapies, there was variation in how they could be accessed; either the therapist visited the client at home and they had individual CBT sessions, or they were invited to attend a group. Some clients found that the group therapy was helpful, others told us that it had an adverse effect on their health as they "took on the problems of the other people in the group".

The service users were keen to point out that they did not always feel that they had a choice of prescription or talking therapy, nor did they have a choice of whether they would prefer to be treated individually or to take part in group therapy. They felt that being able to be properly involved in the decisions about their health is an important factor in improving attendance and compliance, achieving a positive outcome and managing expectations. Some SUs reported that they would prefer that their treatment was not "dictated or prescribed by the medical profession", and that social and psychological interventions should be available options for all older people. Having a good relationship with professional carers in the home setting, or with health or other care professionals in primary or secondary care was important for their confidence and reassurance, and "limiting avoidable stress related flare-ups".

#### Culture, equity and attitude

Older people reported that they are very aware of the **stigma** associated with having mental illness or looking after a spouse or family member with a mental illness. This affected them in that they felt reluctant to go to group therapy, or even to go to the GP in the first place. Because of the perception of stigma, those that were in work said that it affected their relationship with their employer and their work colleagues as their illness was "unmentioned" and no-one would "ask after you, offer to come and visit you at home or even organise and send a get-well card". This was "completely at odds" to being off work due to a physical illness where people know what to expect, how long you might be unwell for and how to help you. In addition to self-imposed isolation due to embarrassment about being unwell, the uncertainty of family, friends and colleagues of how to help or behave would often result in further **isolation**.

Services users of both adult and older people mental health services spoke about the **inequity** between physical and mental health, in terms of funding as well as the way that it is portrayed in society as being something to fear. There was a perception that the empathy and understanding of mental health conditions varied widely amongst different GP practices and that this created variation in what intervention or support patients were offered.

#### Physical health

Both adult and older people often have mental health and other comorbidities including long term conditions such as diabetes, arthritis and heart disease. SUs were keen to point out that their mental health and their physical health was inextricably linked and that living with chronic pain or suffering from another long-term chronic condition such as irritable bowel syndrome could be the cause of depression and anxiety, as well as a factor that might even exacerbate the symptoms of the long-term chronic condition. They highlighted the need for all people with mental illness to be considered as a whole person rather than having their symptoms and diagnoses managed separately.

Service users also expressed a strong appreciation of the relationship that they have with their own doctor or their practice, where they are familiar with the patient, their history and both their physical and mental health needs. Some expressed frustration about GP appointments at which they saw a doctor who did not know them, and who could not address more than one problem in the patient consultation due to time constraints.

#### Carers' needs

Family and carers of adults and older people told us that they needed a whole family approach from support services in order to be able to cope with looking after their relative as well as possible at home or in the community. This needs to recognise the impact of caring on the carers' own physical and mental health, and take into account their own pre-existing health conditions and increasing age. There was a general concern that as the elderly population increased, there would need to be additional provision and alternative infrastructure to be able to support the carers and their mentally ill family members.

# 8.2 Service improvement ideas

When asked about how services could be improved in a way that would make a difference to service users or their carers, the following suggestions were made:

- Provide information, training and workshops for families and carers as well as those iwth mental health disorders to help them be involved in their relatives care and to avoid carers themselves becoming isolated and lonely or frightened that they might be 'doing it wrong'.
- Rather than see a different GP every visit, some service users suggested that seeing another healthcare professional who has an interest in mental health when they go to the GP might be an alternative way of overcoming the issues about confidence and continuity of care.
- Help with practical things like maintaining personal relationships despite having a mental illness, making a will, or knowing how to apply for benefits
- "Need to send out a strong message that people 'can recover' and focus on the positives and treat the circumstances rather than just the diagnosis for instance, solve the loneliness rather than give pills for the depression".
- Support to develop and strengthen communities and neighbourhoods in order to help older people with mental health problems and their carers live at home, without being "isolated, and lonely with nothing to do".
- 'Need to find creative solutions in the community" such as singing groups, animal care, gardening, exercise, dancing and other community centred support.
- Signposting where to go for help or ideas and for friendship. There are community
  navigators but even the navigators also need some practical help with things like
  communication and computer access so they can help others. Allow time for the
  initiative to get started, for people to learn how to make it work and for the community to
  get used to taking advantage of it.

## 8.3 Follow up consultation with providers and third sector organisations

To complement our engagement with service users and steering group representatives, we organised a meeting with organisations providing services to people with mental health problems; both statutory and third sector. All invitees were funded by statutory organisations to deliver services to adults with mental health disorders. The purpose of this meeting was to confirm the findings so far and to elicit realistic and pragmatic ideas for service improvement and service user outcomes.

The information received from providers contributed to the overall picture of need of adults with autism, personality disorder or dual diagnosis, alongside quantitative data, patient and carers perspectives and national guidelines for best practice in delivering mental health services for these people. It is important to note that the numbers who took part in the providers meeting was limited.

The main points made by the twelve service providers who attended this meeting were that:

- Statutory services manage their caseloads by discharging patients as promptly as is appropriate. This often provokes anxiety in service users, who see themselves as abandoned and may not be made aware of third sector providers that could support them. This anxiety may itself contribute to relapse. In addition, the mean-tested nature of social care means that the cost implications of NHS care ending can be daunting. Similarly, when social care assess and review needs any changes, particularly a reduction in assessed need, should be clearly explained and understood by all agencies, and the individual involved.
- 2. When people with mental health problems relapse, there is often no rapid means of referring them back to mental health service. Things working well are often dependent on a care plan that covers the possibility of relapse (which may be absent) and/or a general practitioner with a special interest in mental health issues. Could there be a facilitated means of referring back those with a fairly recent history of mental health problems to avoid the crises and consequent problems that can result from delay?
- 3. Statutory agencies accept the need for third sector organisations and recognise that they increasingly provide services which the public sector can no longer feasibly include. Despite this interdependence and transfer of responsibility, the relationship is sometimes asymmetric. As a result, when third sector organisations see a client's condition deteriorating, they may not be able to engage mental health services in developing a response. The organisations work in partnership, but it is not one of equals. For the increasing transfer of responsibility to the third sector to deliver good results for service users, statutory organisations need to respect more visibly the judgements, expertise and authority of third sector ones, react more energetically when they draw attention to a client's needs and share information more freely.
- 4. When service users' assessed needs are reviewed by social care they may reduce needs without being clear why.
- 5. There are problems with the way that the dual diagnosis protocol works across Cambridgeshire as both substance misuse and mental health providers might regard people with dual diagnosis as unsuitable for their respective services, leaving the individual adrift. The decision as to which of the two diagnoses is predominant is sometimes hard to reach objectively and may have important cost implications, but there is no means of adjudicating or arbitrating contested or mutually incompatible decisions by treatment agencies. This is partly because there is no dual diagnosis service specifically commissioned. An alternative approach would be a single service for those who had more severe dual diagnoses, required to take responsibility for those neither service would itself treat. This service would either treat the patient, or assign them to one or other service.

#### 8.4 Other sources of information<sup>90</sup>

In 2011, an Adult Autism Development Project Report produced on behalf of Red to Green, surveyed the needs of 50 people on the autistic spectrum. It found several unmet needs, which were particularly acute amongst those who were not accessing social care services. These needs overlap a number of areas relevant to other chapters to this report, but as they are wider determinants of health, they are summarised in this section:

- Difficulties with identification and diagnosis of the condition.
- Lack of social integration including access to support groups.
- Lack of training amongst staff they came into contact with.
- Lack of practical life skills such as shopping, travelling, management of money and access to benefits.
- Few employment opportunities and a lack of support once in employment.
- Difficulties in accessing appropriate housing; conflict with parents for those still living at home and a lack of supported living opportunities.

A recent 2013 report, by Cambridgeshire self-advocacy group, Speak-Out Spectrum, summarised the situations of 13 people on the autistic spectrum. More than two-thirds still lived with their parents; over half were in receipt of benefits and most wanted additional support with getting a job or with social skills.

<sup>&</sup>lt;sup>90</sup> Email communication received in lieu of being able to attend the service provider meeting on 24<sup>th</sup> February 2014

# 9. Key findings

- 1. Due to an increasing population there will be an increase in the number of people with these mental health disorders within a few years. However, the resources available from statutory agencies for health services given the current financial restraints will at best remain the same, requiring the development of new service models to meet need. A holistic approach is vital.
- 2. National guidance in the form of Clinical Guidelines and Quality Standards published by NICE describe in detail what patients should receive from NHS and social services. Existing service specifications from commissioners describe what should be available from NHS mental health services, though not in the case of Autistic Spectrum Condition. However, the extent to which national guidance and local service specifications are followed in practice was not reviewed as part of this JSNA. This should form part of a future work programme.
- 3. We found no reliably evaluated early interventions for people with ASC, personality disorder and dual diagnosis published since the most recent NICE guidance. Therefore the most recent NICE guidance should be used as the basis for early intervention work.
- 4. Adults with severe mental illness have a substantially reduced life expectancy due to both mental and physical ill health with a significant proportion of excess deaths being associated with physical conditions. A proportion of those within the specific conditions considered in this report are likely to have severe mental illness. In addition, there is often inequality of access to health services for physical illness for people who use mental health services. People with mental illness need equal access in order to improve their physical health problems and reduce their risk factors.
- 5. For adults with autism, a high-quality diagnostic service is available from CPFT. However, services to support adults with autism and their carers in the community are sometimes fragmented and difficult to access. The recently published quality standard<sup>91</sup> for autism (January 2014) is a good basis on which to review the commissioned service specification and to review the services provided for adults with autism.
- 6. There are strong indications of problems in services for people with dual diagnosis. There are examples from both service providers and service users which suggest that sometimes, neither the substance misuse service nor mental health services are apparently willing to take on patients with more severe dual diagnoses, with no system for adjudication in such cases. As a result, clients are left with no service.
  - a. Commissioners should consider a review of services for dual diagnosis. An option, recommended by stakeholders, is to establish a jointly funded single service for those who had more severe dual diagnoses, which would take responsibility for those neither service would itself treat. This service would either treat the client, or assign them to one or other service.

<sup>&</sup>lt;sup>91</sup> Autism. QS51, 2014. <u>http://guidance.nice.org.uk/QS51</u>

- b. NICE recommends that "Specialist substance misuse services should work closely with secondary care mental health services to develop local protocols derived from this guideline for adults and young people with psychosis and coexisting substance misuse. The agreed local protocols should set out responsibilities and processes for assessment, referral, treatment and shared care across the whole care pathway<sup>92</sup>." Although such a protocol exists in Cambridgeshire, its implementation appears to be incomplete.
- 7. Adults with mental disorders, including personality disorder, dual diagnosis and autism, sometimes experience mental health crisis and need help quickly to stop them harming themselves or others. The Crisis Care Concordat<sup>93</sup> is aimed at making sure that people experiencing a mental health crisis receive an appropriate emergency mental health service. It reflects a new requirement for the NHS that "every community has plans to ensure no one in mental health crisis will be turned away from health services"<sup>94</sup>. There should be local implementation of the Crisis Care Concordat to ensure that adults in mental health crisis are able to recover, and that admissions to hospital or to prison might be avoided.
- 8. No information on activity levels and expenditure patterns by the main NHS mental health service provider in Cambridgeshire was available within the timescale of this report. This impedes service planning and evaluation by commissioners. It also limited the extent to which we can comment on patterns of service delivery. The routinely collected anonymised national minimum dataset should be available in a timely and accessible format to providers and commissioners of mental health services.

<sup>&</sup>lt;sup>92</sup> Psychosis with coexisting substance misuse: Assessment and management in adults and young people. CG120, 2011. <u>www.nice.org.uk/CG120</u>

<sup>&</sup>lt;sup>93</sup> Department of Health and Home Office <u>Mental Health Crisis Care Concordat - Improving outcomes for people</u> <u>experiencing mental health crisis</u> February 2014

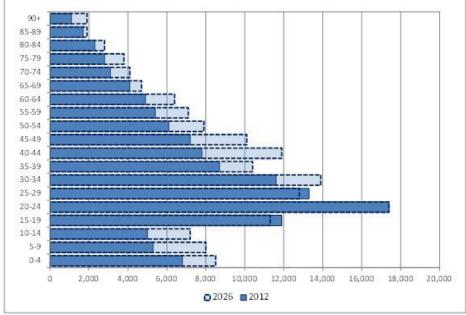
<sup>&</sup>lt;sup>94</sup> Department of Health The Mandate: A mandate from the government to NHS England: April 2014 to march 2015. <u>https://www.gov.uk/government/publications/nhs-mandate-2014-to-2015</u>

#### Appendix 1: Details of population projections

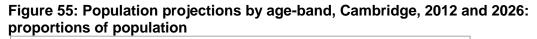
Cambridge City shows an unusual demographic pattern, with a large number of people of younger working age and fewer children and older people. This reflects the influence of the City's educational institutions. These differences are projected to become less apparent by 2026, though this is subject to trends which are hard to anticipate.

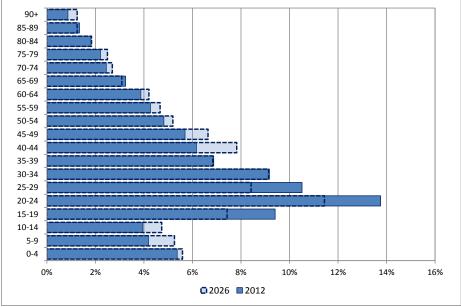
Like all parts of the County, Cambridge's population shows increases in the older age-bands with time (Figure 54 and 55).

Figure 54: Population projections by age-band, Cambridge, 2012 and 2026: numbers of people



Source: Cambridgeshire County Council

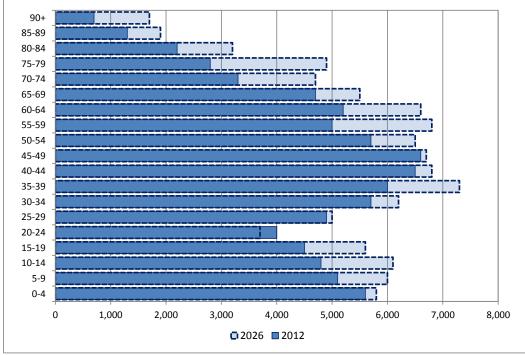




Source: Cambridgeshire County Council

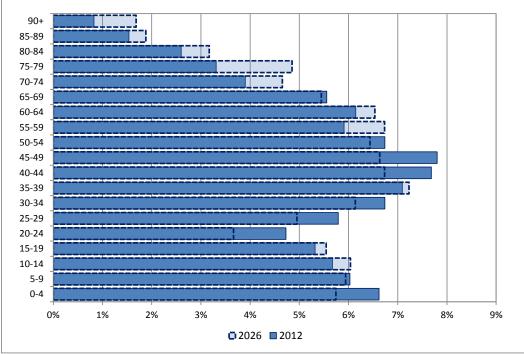
East Cambridgeshire has a more typical population profile, though with relatively few people between 20 and 40 years. The profile is expected to become more even over time, with growth in all age groups except 20 to 24 years.





Source: Cambridgeshire County Council

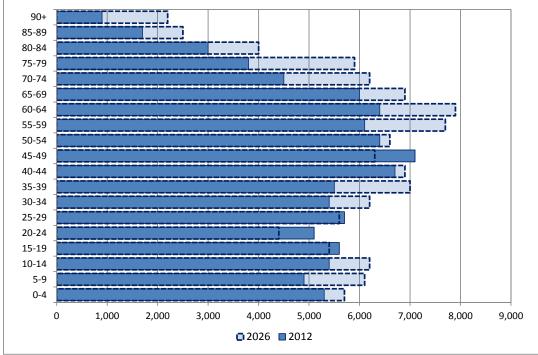




Source: Cambridgeshire County Council

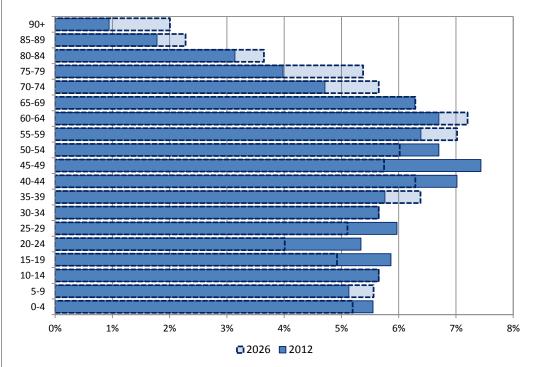
Fenland's demographic profile is fairly even across the main age categories and shows growth in most age groups.





Source: Cambridgeshire County Council

Figure 59: Population projections by age-band, Fenland, 2012 and 2026: proportions of population



Source: Cambridgeshire County Council

The demographic position and projection in Huntingdonshire is similar to that in Fenland, though with less, or no, growth in some adult working age categories.

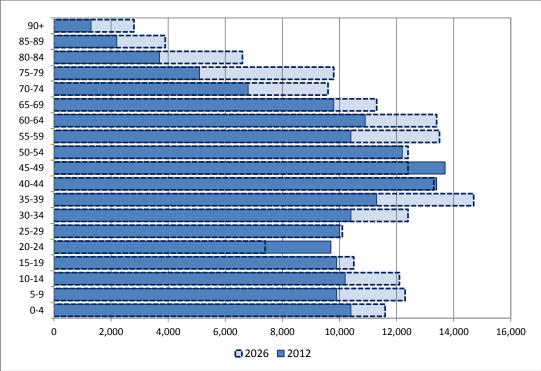
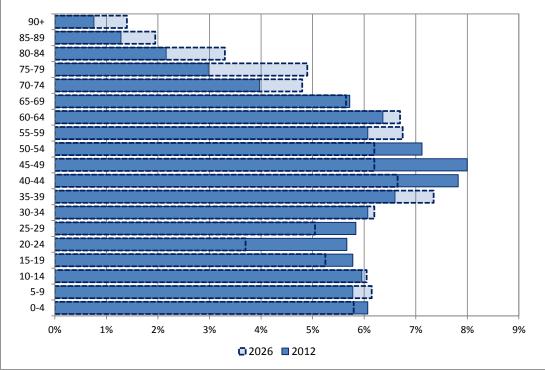


Figure 60: Population projections by age-band, Huntingdonshire, 2012 and 2026: numbers of people

Source: Cambridgeshire County Council





Source: Cambridgeshire County Council

South Cambridgeshire has relatively few people in the younger adult age bands. Increases are expected in all age-groups except 20 to 24 year olds by 2026. All but one age-band are expected to show increases in absolute numbers by 2026, with older adults becoming relatively more numerous.

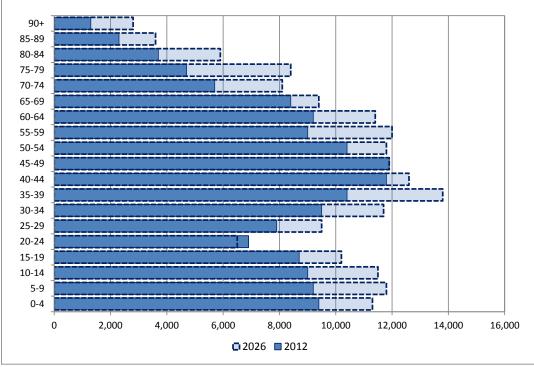
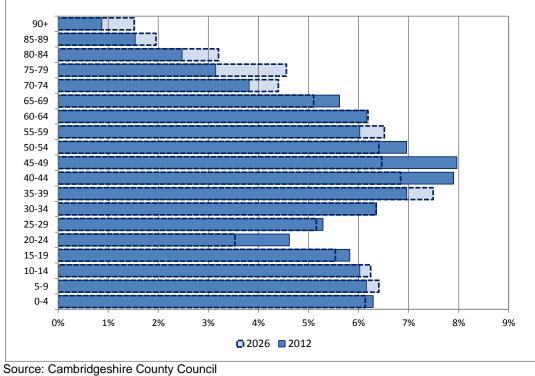


Figure 62: Population projections by age-band, South Cambridgeshire, 2012 and 2026: numbers of people

Source: Cambridgeshire County Council





# **Appendix 2: Search Strategies**

This appendix sets out the search strategy used for the evidence review in this JSNA.

### **Adults with Autism**

- 1. Autistic Disorder/
- 2. (autism or autistic\*).ti,ab.
- 3. Asperger Syndrome/
- 4. asperger\*.ti,ab.
- 5. 1 or 2 or 3 or 4
- 6. Primary Prevention/
- 7. preventive health services/ or secondary prevention/
- 8. "early intervention (education)"/ or exp health education/ or exp health promotion/
- 9. prevent\*.ti,ab.
- 10. ((patient or health or consumer) adj3 educat\*).ti,ab.
- 11. (health adj3 promot\*).ti,ab.
- 12. ((early or multifacet\* or multi-facet\* or non-pharmacolo\* or nonpharmacol\*) adj2 intervention\*).ti,ab.
- 13. 6 or 7 or 8 or 9 or 10 or 11 or 12
- 14. 5 and 13
- 15. Autistic Disorder/pc or Asperger Syndrome/pc
- 16. 14 or 15
- 17. limit 16 to "all adult (19 plus years)"
- 18. adult\*.ti,ab.
- 19. 16 and 18
- 20. 17 or 19
- 21. limit 20 to "reviews (maximizes specificity)"
- 22. limit 20 to "therapy (best balance of sensitivity and specificity)"
- 1. exp Child Development Disorders, Pervasive/
- 2. (autism or autistic\* or asperger\*).ti,ab.
- 3. 1 or 2
- 4. limit 3 to "all adult (19 plus years)"
- 5. adult\*.ti,ab.
- 6. ((old\* or age\* or late\*) adj3 diagnos\*).ti,ab.
- 7.5 or 6
- 8. 3 and 7
- 9. 4 or 8
- 10. Disease Progression/
- 11. (progress\* adj3 (disease\* or disorder\* or symptom\*)).ti,ab.
- 12. ((reduc\* or alleviat\* or improv\* or chang\*) adj3 symptom\*).ti,ab.
- 13. ((reduc\* or slow\* or low\* or chang\* or modif\* or improv\*) adj3 incidence).ti,ab.
- 14. "Activities of Daily Living"/
- 15. "activities of daily living".ti,ab.
- 16. independent living/ or social participation/
- 17. ((live\* or living) adj2 (independent\* or alone)).ti,ab.
- 18. Interpersonal Relations/
- 19. ((social\* or interpersonal) adj2 (participat\* or interact\* or adjust\*)).ti,ab.
- 20. social behavior/ or social adjustment/ or social isolation/
- 21. work/ or return to work/
- 22. (work or working or vocational\*).ti,ab.
- 23. "Quality of Life"/
- 24. "quality of life".ti,ab.
- 25. exp Psychotherapy/
- 26. ((psycholog\* or psychosoc\* or social\* or educat\* or behavio\* or nonpharma\* or non-pharma\*) adj2 (intervention\* or therap\* or treatment\*)).ti,ab.

27. 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26

- 28. 9 and 27
- 29. exp Child Development Disorders, Pervasive/px [Psychology]
- 30. limit 29 to "all adult (19 plus years)"
- 31. 7 and 29
- 32. 30 or 31
- 33. 28 or 32
- 34. limit 33 to (english language and yr="2003 -Current")
- 35. limit 34 to "reviews (maximizes specificity)"
- 36. limit 34 to "therapy (best balance of sensitivity and specificity)"
- 37. 35 or 36

#### Adults with Personality Disorder

- 1. exp Personality Disorders/
- 2. (personality adj2 disorder\*).ti,ab.
- 3. 1 or 2
- 4. Primary Prevention/
- 5. preventive health services/ or secondary prevention/
- 6. "early intervention (education)"/ or exp health education/ or exp health promotion/
- 7. prevent\*.ti,ab.
- 8. ((patient or health or consumer) adj3 educat\*).ti,ab.
- 9. (health adj3 promot\*).ti,ab.
- 10. ((early or multifacet\* or multi-facet\* or non-pharmacolo\* or nonpharmacol\*) adj2 intervention\*).ti,ab.
- 11. 4 or 5 or 6 or 7 or 8 or 9 or 10
- 12. 3 and 11
- 13. exp Personality Disorders/pc [Prevention & Control]
- 14. 12 or 13
- 15. limit 14 to (english language and yr="2003 -Current")
- 16. limit 15 to "reviews (maximizes specificity)"
- 17. limit 15 to "therapy (best balance of sensitivity and specificity)"
- 18. 16 or 17
- 1. exp Personality Disorders/
- 2. (personality adj2 disorder\*).ti,ab.
- 3. 1 or 2
- 4. disease progression/
- 5. (progress\* adj3 (disease\* or disorder\* or symptom\*)).ti,ab.
- 6. ((reduc\* or low\* or chang\* or modif\* or improv\*) adj3 incidence).ti,ab.
- 7. ((reduc\* or alleviat\* or improv\* or chang\*) adj3 symptom\*).ti,ab.
- 8. "Activities of Daily Living"/
- 9. "activities of daily living".ti,ab.
- 10. exp Self-Injurious Behavior/pc [Prevention & Control]
- 11. exp \*Self-Injurious Behavior/
- 12. \*Mortality/
- 13. \*Survival/ or \*Survival Rate/
- 14. (suicide or suicidal).ti,ab.
- 15. (mortality or survival).ti.
- 16. hospitalization/ or patient admission/
- 17. hospitali?ation.ti,ab.
- 18. ((hospital or patient) adj2 (admission? or admitted)).ti,ab.
- 19. crime/ or violence/
- 20. (crime or violence or violent).ti,ab.
- 21. 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20

23. limit 22 to (english language and yr="2003 -Current")

24. limit 23 to "reviews (maximizes specificity)"

25. limit 23 to "therapy (best balance of sensitivity and specificity)"

26. 24 or 25

### Adults with Dual Diagnosis

1. "Diagnosis, Dual (Psychiatry)"/

2. mental disorders/ or exp \*anxiety disorders/ or exp \*delirium, dementia, amnestic, cognitive disorders/ or exp \*dissociative disorders/ or exp \*eating disorders/ or exp \*factitious disorders/ or exp \*impulse control disorders/ or exp \*mood disorders/ or exp \*neurotic disorders/ or exp \*personality disorders/ or exp \*"schizophrenia and disorders with psychotic features"/ or exp \*"sexual and gender disorders"/ or exp \*sleep disorders/ or exp \*somatoform disorders/

3. exp \*Substance-Related Disorders/

4. 2 and 3

5. ((substance\* or drug\* or alcohol\* or addict\* or abuse\* or dependence) and (mental\* ill\* or mental disorder\* or depress\* or anxiety or bipolar\* or schizophren\* or psychos\* or psychotic\* or eating disorder\* or amorexi\* or bulimi\*)).ti.

6. dual diagnosis.ti.

7. 1 or 4 or 5 or 6

8. Primary Prevention/

9. preventive health services/ or secondary prevention/

10. "early intervention (education)"/ or exp health education/ or exp health promotion/

11. prevent\*.ti,ab.

12. ((patient or health or consumer) adj3 educat\*).ti,ab.

13. (health adj3 promot\*).ti,ab.

14. ((early or multifacet\* or multi-facet\* or non-pharmacolo\* or nonpharmacol\*) adj2 intervention\*).ti,ab.

15. 8 or 9 or 10 or 11 or 12 or 13 or 14

16. 7 and 15

17. (mental disorders/pc or exp \*anxiety disorders/pc or exp \*delirium, dementia, amnestic, cognitive disorders/pc or exp \*dissociative disorders/pc or exp \*eating disorders/pc or exp \*factitious disorders/pc or exp \*impulse control disorders/pc or exp \*mood disorders/pc or exp \*neurotic disorders/pc or exp \*personality disorders/pc or exp \*"schizophrenia and disorders with psychotic features"/pc or exp \*"sexual and gender disorders"/pc or exp \*sleep disorders/pc or exp \*somatoform disorders/pc) and exp \*Substance-Related Disorders/pc 18. 16 or 17

19. limit 18 to (english language and yr="2003 -Current")

20. limit 19 to "reviews (maximizes specificity)"

21. limit 19 to "therapy (maximizes specificity)"

#### 1. "Diagnosis, Dual (Psychiatry)"/

2. \*mental disorders/ or exp \*anxiety disorders/ or exp \*delirium, dementia, amnestic, cognitive disorders/ or exp \*dissociative disorders/ or exp \*eating disorders/ or exp \*factitious disorders/ or exp \*impulse control disorders/ or exp \*mood disorders/ or exp \*neurotic disorders/ or exp \*personality disorders/ or exp \*"schizophrenia and disorders with psychotic features"/ or exp \*"sexual and gender disorders"/ or exp \*sleep disorders/ or exp \*somatoform disorders/

3. exp \*Substance-Related Disorders/

4. 2 and 3

5. ((substance\* or drug\* or alcohol\* or addict\* or abuse\* or dependence) and (mental\* ill\* or mental disorder\* or depress\* or anxiety or bipolar\* or schizophren\* or psychos\* or psychotic\* or eating disorder\* or anorexi\* or bulimi\*)).ti.

6. dual diagnosis.ti.

7. 1 or 4 or 5 or 6

8. disease progression/

- 9. (progress\* adj3 (disease\* or disorder\* or symptom\*)).ti,ab.
- 10. ((reduc\* or low\* or chang\* or modif\* or improv\*) adj3 incidence).ti,ab.
- 11. ((reduc\* or alleviat\* or improv\* or chang\*) adj3 symptom\*).ti,ab.
- 12. "Activities of Daily Living"/
- 13. "activities of daily living".ti,ab.
- 14. Independent Living/
- 15. ((live or living) adj2 independent\*).ti,ab.
- 16. independence.ti,ab.
- 17. relaps\*.ti,ab.
- 18. hospitalization/ or patient admission/
- 19. ((hospital\* or patient) adj2 (admission or admitted)).ti,ab.
- 20. Substance Abuse Treatment Centers/
- 21. Survival/ or Survival Rate/
- 22. mortality/
- 23. (survival or mortality or death?).ti,ab.
- 24. exp Self-Injurious Behavior/
- 25. suicid\*.ti,ab.
- 26. crime/ or violence/
- 27. (crime or violence or violent).ti,ab.
- 28. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
- or 24 or 25 or 26 or 27
- 29. 7 and 28
- 30. limit 29 to (english language and yr="2003 -Current")
- 31. limit 30 to "reviews (maximizes specificity)"
- 32. limit 30 to "therapy (maximizes specificity)"

# Appendix 3 – Additional information Borderline and Antisocial personality disorder (taken from NICE guidance CG78 & CG77)

**Borderline personality disorder** is characterised by significant instability of interpersonal relationships, self-image and mood, and impulsive behaviour. There is a pattern of sometimes rapid fluctuation from periods of confidence to despair, with fear of abandonment and rejection, and a strong tendency towards suicidal thinking and self-harm. Transient psychotic symptoms, including brief delusions and hallucinations, may also be present. It is also associated with substantial impairment of social, psychological and occupational functioning and quality of life. People with borderline personality disorder are particularly at risk of suicide.

The extent of the emotional and behavioural problems experienced by people with borderline personality disorder varies considerably. Some people with borderline personality disorder are able to sustain some relationships and occupational activities. People with more severe forms experience very high levels of emotional distress. They have repeated crises, which can involve self-harm and impulsive aggression. They also have high levels of comorbidity, including other personality disorders, and are frequent users of psychiatric and acute hospital emergency services.

People with **antisocial personality disorder (AsPD)** exhibit traits of impulsivity, high negative emotionality, low conscientiousness and associated behaviours including irresponsible and exploitative behaviour, recklessness and deceitfulness. This is manifest in unstable interpersonal relationships, disregard for the consequences of one's behaviour, a failure to learn from experience, egocentricity and a disregard for the feelings of others. The condition is associated with a wide range of interpersonal and social disturbance.

Criminal behaviour is central to the definition of antisocial personality disorder, although it is often the culmination of previous and long-standing difficulties, such as socioeconomic, educational and family problems. Antisocial personality disorder therefore amounts to more than criminal behaviour alone, otherwise everyone convicted of a criminal offence would meet the criteria for antisocial personality disorder and a diagnosis of antisocial personality disorder would be rare in people with no criminal history. This is not the case. The prevalence of antisocial personality disorder among prisoners is slightly less than 50%. It is estimated in epidemiological studies in the community that only 47% of people who meet the criteria for antisocial personality disorder have significant arrest records. A history of aggression, unemployment and promiscuity were more common than serious crimes among people with antisocial personality disorder.