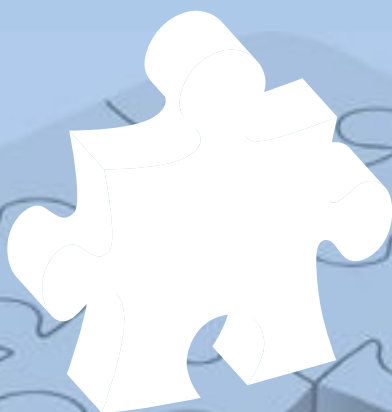


Emotional and Psychological Support and Care in Diabetes

Report from the emotional and
psychological support working group of
NHS Diabetes and Diabetes UK



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Foreword

Patient-centred care is at the heart of the Diabetes National Service Framework (NSF). Children, young people and adults living with diabetes have a crucial role in managing their own care and supporting such self care should be central to any local diabetes service. People with diabetes have a significantly increased risk of depression, anxiety and eating disorders, which can limit their ability to self manage their condition, especially as such self care requires motivation and behaviour change to achieve the best possible quality of life. Also the families of children and young people play a major role in supporting care.

The former Healthcare Commission's report *Managing Diabetes; Improving services for people with diabetes* (July 2007) showed clearly that we were achieving the biomedical targets that had been set, whereas targets around discussing needs and planning care were not well developed.

The provision of emotional and psychological treatment and support has been found to reduce psychological distress and improve health related outcomes and we have been working hard to make such support more widely available across the NHS, such as through the Improving Access to Psychological Therapies (IAPT) programme, which has seen major investment over recent years.

However, there is more that can be done to improve the emotional wellbeing of people with diabetes. The need for training and support for healthcare professionals, and for the allocation of sufficient time for consultations, are key requirements to develop emotional and psychological support and care. NHS Diabetes is looking at this issue and how such services can be better commissioned in the future.

This report sets out the findings of a working group established to examine the current challenges and seek solutions to them. It provides guidance and makes recommendations in a number of areas, including commissioning, organisation of care, provision of services and workforce.

We would like to thank the members of the joint NHS Diabetes and Diabetes UK Emotional and Psychological Support and Care in Diabetes Working Group for developing the guidance contained in this report. It will help diabetes teams to offer a co-ordinated service that supports people with diabetes to better self-manage their condition and to experience the best possible quality of life.



A handwritten signature in black ink that reads "Anna Morton".

Anna Morton



A handwritten signature in black ink that reads "George Alberti".

Professor Sir George Alberti

Executive summary

- In the United Kingdom, 2.6 million people have diabetes, including over 22,000 young people under the age of seventeen in England. Up to 500,000 people have the condition but are unaware of it. The number of people with diabetes in the UK is predicted to grow to four million by 2025 with a doubling of the number of children diagnosed under five years of age. Diabetes has a major impact on the health and wellbeing of the population. The needs of individuals living with diabetes, and those who care for them, are therefore vital concerns of health and social care policy.
- The effects of diabetes on the individual are complex. Diabetes is a long term condition which requires careful self-management to minimise the risks of physical illness and complications. Different interventions are required depending on the type of diabetes and complexity of need. On a day-to-day basis, diabetes interferes with the routines of daily life and constrains the choices that individuals are able to make. Not surprisingly, the impact of diabetes on emotional and psychological wellbeing can be profound.
- The emotional and psychological needs of people living with diabetes, and those who care for them, are complex. They can be described using a 'pyramid model' which illustrates the diversity of need and the broadly inverse relationship between prevalence and severity of need. At the base of the pyramid (level 1) needs are common but not severe, such as general difficulties with coping, whereas at the top of the pyramid (level 5) needs are severe, such as may require specialist psychiatric/psychological intervention, but relatively infrequent. The model, which is underpinned by a wealth of evidence, encompasses conditions that are formally diagnosable and those that are not. It should also be remembered that people with existing severe mental illness (SMI) such as schizophrenia are at higher risk of developing Type 2 diabetes and its complications.
- The pyramid model is invaluable in conceptualising the diversity of need for the population and the individual living with diabetes who is likely to have different needs over the course of his or her life. Emotional and psychological needs may be greater at key times such as diagnosis, the developmental stages during childhood, during transition from child to adult services, during pregnancy, at the onset of complications or due to other changes and pressures in life circumstances. The reality of need at any one time will always be shaped by the demands of the condition, the demands of life, and the interaction between the two. Any intensification of emotional or psychological need is likely to make everyday self-management, the core of diabetes care, harder to achieve.
- Services that seek to meet these needs must also balance a population perspective, recognising the diversity of emotional and psychological need across the population of people living with diabetes, with responsiveness to individual need. This is acknowledged in national policy documents, including the Diabetes National Service Framework, and NICE guidance which point to an integrated approach to meeting needs as a key strategy. This requires both a closer partnership between diabetes services and mental health and psychology services and improvements in the skills of the multidisciplinary teams providing services to people with diabetes and those who care for them.
- In practice, there are major gaps in the provision of emotional and psychological care to people with diabetes. The national Minding the Gap survey found that 85 per cent of people with diabetes in the UK have either no defined access to psychological support and care, or at best

access to a local generic mental health service only. The standards set out within the diabetes National Service Framework and the NICE guidance provide a clear statement of the level and quality of services that people with diabetes ought to expect. Yet less than 3 per cent of diabetes services meet all six psychologically-relevant NICE recommendations and National Service Framework standards, and 26 per cent do not meet any. There are many examples of good practice in delivering integrated emotional and psychological care to people with diabetes in the UK, some of which are described in detail in this report, but the extent of the gaps in provision, and the inequalities in access to services, must be addressed.

- There is substantial evidence of the effectiveness of interventions to address the emotional and psychological needs of people with diabetes, though this evidence primarily concerns the lower levels of the pyramid model. This evidence includes interventions which improve self-management, relieve anxiety and distress, and overcome milder forms of depression and eating problems. They range from individual training to group therapy and peer support. There is less available evidence from research, specifically in relation to people with diabetes, regarding the effects of interventions for more severe forms of psychological and psychiatric problems.
 - This evidence is of particular value to commissioners who face the difficult task of specifying services that will meet the complexity of the emotional and psychological care needs of children, young people and adults with diabetes and those who care for them. Commissioners should draw on local needs assessment (to ensure that they have an
- accurate understanding of local needs), national frameworks and guidance (to ensure that services are designed to appropriate standards) and good practice in service specification. Decisions about local priorities and the specification of interventions to meet the needs of the local population are always a matter for local determination and should be informed by the views of local service users, including the voices of those seldom heard.
- The commissioning and delivery of services that meet the full range of emotional and psychological needs of people with diabetes require that the skills and competences of the staff who provide these services are appropriate to the task. In practice, this means that a range of skills are needed appropriate to each of the five levels of need defined by the pyramid model, including skills in diabetes care, psychological support and care planning. The specification of competences enables the identification of skills gaps, the design of education and training, and the development of job descriptions and role profiles. Competences are invaluable for embedding psychological support in all care pathways and for clarifying the boundaries of every professional's role.
 - The recommendations in this report cover commissioning, workforce planning, service delivery, policy and research. Taken together, they challenge and encourage everyone involved in diabetes care to seek a transformation of diabetes services such that emotional and psychological needs are recognised as essential to the wellbeing of people with diabetes and vital to their self-management and long term physical health.

1. Introduction

Diabetes has a profound impact on the population of the United Kingdom: 2.6 million people have a diagnosis of diabetes, including over 22,000 children under the age of seventeen in England. Up to 500,000 people have the condition but are unaware of it. The number of people with diabetes in the UK is predicted to grow to four million by 2025 with a doubling of the number of children diagnosed under five years of age.

Diabetes is a complex condition that presents substantial challenges for every individual living with the condition. Effective self-management of diabetes is critical to the achievement of healthy, independent and flexible day-to-day living but this requires personal motivation and changes in behaviour and routines. Emotional and psychological wellbeing is compromised when personal efforts to meet these challenges do not succeed as anticipated, or when the complications of diabetes take their toll on physical health.

Several factors affect the emotional and psychological wellbeing of a person with diabetes. These include the degree to which any individual accepts their diagnosis, adjusts to the demands of the self-care routine, and copes with progression of the condition, which potentially includes the development of diabetes-related complications. For children and young people developmental stages of life can influence the ability to manage diabetes which itself can impact

on the development of the child.¹ In addition, an individual may have emotional and psychological needs unrelated to diabetes that affect their wellbeing and ability to self-manage the condition.

The prevalence of psychological conditions such as depression, anxiety and eating disorders is significantly higher among people with diabetes than in the general population.² Depression is at least twice as common in people with diabetes than in the general population³ but goes undetected in 30-50 per cent of cases in both primary⁴ and secondary care.⁵ It is estimated that 41 per cent of people with diabetes experience poor psychological wellbeing⁶ and many people with diabetes have psychological needs that do not satisfy criteria for a formal diagnosis.⁷ Evidence from the Diabetes UK member survey indicates that people with diabetes want and need access to emotional and psychological support and care but are not always able to access appropriate services.⁸

Poor emotional and psychological wellbeing in people with diabetes is associated with sub-optimal glycaemic control, increasing the risk of the development of diabetes-related complications.⁹ Such complications have multiple impacts including reduced quality of life for the individual with diabetes, increased mortality,¹⁰ increased healthcare costs¹¹ and lost productivity.¹²

¹ Christie D and Viner RM (2005)

² Lustman et al (2000), Grigsby et al (2002), Colton et al (2004), Goodwin et al (2003), Anderson et al (2001), Ali et al (2006), Das-Munshi et al (2007), Gavard et al (1993)

³ Lustman et al (2000), Anderson et al (2001), Ali et al (2006), Das-Munshi et al (2007), Gavard et al (1993)

⁴ Ali et al (2006)

⁵ Lustmann and Harper (1987), Penn et al (1997)

⁶ Mayou et al (1991), Peyrot et al (2005)

⁷ Trigwell et al (2008)

⁸ Diabetes UK (2009a)

⁹ Polonsky et al (1995), Lustman et al (2000), Ciechanowski et al (2000), de Groot et al (2001), Rosenthal et al (1998), Clouse et al (2003)

¹⁰ Katon et al (2005)

¹¹ Egede and Zheng (2003), Golney et al (2004), Ciechanowski et al (2000)

¹² Egede (2007), Egede (2004)

¹³ Tankova et al (2004)

Access to diabetes-related information and education can help reduce anxiety related to managing diabetes, promote coping and improve clinical outcomes.¹³ The provision of emotional and psychological treatment and support reduces psychological distress¹⁴ and improves health-related outcomes¹⁵ for people with diabetes. Treatment of conditions such as depression in people with diabetes has been shown to lead to improvements in psychological and other health-related outcomes¹⁶ and reduce healthcare costs¹⁷. For children, young people and adults alike, a key challenge in the chronic care management of diabetes is establishing and maintaining the motivation that enables them to achieve both effective management of the individual's diabetes and emotional wellbeing of all members of the family.¹⁸

The International Society of Paediatric and Adolescent Diabetes (ISPAD) consensus guidelines 2000 stated that 'psychological factors are the most important influences affecting the care and management of diabetes and went onto make the following three recommendations:

- Social workers and psychologists should be part of the interdisciplinary healthcare team
- Overt psychological problems in young persons or family members should receive support from the diabetes care team and attention from expert mental health professionals
- The diabetes team should receive training in the recognition, identification and provision of information and counselling on psychosocial problems related to diabetes.

The most recent consensus guidelines made further recommendations building upon these.¹⁹

It is therefore compelling from both a clinical and financial perspective to provide effective services for such a significant proportion of the population. Services must meet the emotional and psychological needs of people with diabetes and support them to self-manage their condition.

Yet significant gaps remain in the provision of psychological support and care for people with diabetes in the UK.²⁰ These gaps will only be addressed if primary care, mental health and diabetes services are conceived, planned and delivered in an integrated manner.

In order to develop guidance on how emotional and psychological support can best be provided to people with diabetes, the joint Diabetes UK and NHS Diabetes Psychological and Emotional Support Working Group was established in February 2008. The remit of the group was to:

- Develop functional definitions of emotional and psychological support, sensitive to equality issues and informed by appropriate strategic co-ordination
- Identify relevant policy and national guidance and maximise strategic co-ordination on development of key service principles and functional requirements
- Develop criteria, sensitive to equality issues, to develop and assess services
- Gather and disseminate good practice models and care pathways that meet these criteria
- Identify competences for people with diabetes and those providing emotional and psychological support to facilitate optimal self-care
- Identify what needs to be done to enable the implementation of service models which meet consensus criteria and competences
- Identify commissioning and audit tools necessary to commission and monitor services
- Develop tools and strategies for promotion of emotionally and psychologically informed services to support self management throughout the diabetes community

This report explores the many issues relevant to integrating emotional and psychological care within diabetes services. We hope that it assists in the development of high quality, sensitive services that meet the emotional and psychological needs

¹⁴ Fisher et al (2007), Ismail et al (2007), Ismail et al (2004), Winkley et al (2006)

¹⁵ Goodnick et al (1995), Goodnick et al (1997), Lustman et al (1998), Lustman et al (2000), Lustman et al (2005)


¹⁶ Lustman and Clouse (2005), Ismail et al (2004), Goodnick et al (1995), Goodnick et al (1997), Lustman et al (1998), Lustman et al (2000)

¹⁷ Simon et al (2007)

¹⁸ Viner et al (2003)

¹⁹ ISPAD (2000)

²⁰ Trigwell et al (2008)



of people living with diabetes, and that it may be an inspiration to those who are developing similar services to meet the needs of people with other long term conditions.

Case studies of existing services are included throughout the document, illustrating the many ways in which professionals and people with diabetes have crafted effective responses to the complexity of personal emotional and psychological need. We warmly welcome the submission of further examples for inclusion on Diabetes UK's Sharing Practice database.

Simon O'Neill

Director of Care, Information and Advocacy,
Diabetes UK and chair of the Working Group²¹

²¹ A full list of contributors to the report is included in Appendix A

2. Emotional and psychological needs

The emotional and psychological needs of people with diabetes can be described on a continuum from healthy coping, through diabetes-related distress, to psychological and psychiatric conditions. The broad aim of emotional and psychological care is to support the individual with diabetes and his or her family and other carers in preventing and reducing any distress that has a negative impact on the individual's general wellbeing and ability to self-manage their diabetes effectively.

Maintaining Psychological Health

Supporting people with diabetes to self-manage their condition through the provision of education, information, and emotional support can help to prevent the development or exacerbation of psychological need. Supported self-management helps individuals to develop the skills and confidence to manage their diabetes and cope with the challenges of daily decision making. It has been found to lead to positive outcomes for the individual, including improved feelings of wellbeing and coping skills,²² reductions in the anxiety associated with managing diabetes,²³ improved quality of life and health outcomes, and improved knowledge.²⁴ Where there is a greater reliance upon parental or carer support such as in the very young or older people, psychological support should focus on the wider systems of care.

The range and complexity of need

Emotional and psychological needs are reported both by people with diagnosed diabetes and by those who live with, or care for, somebody who has the condition. These needs are determined by many factors, reflecting the profound interaction of diabetes with the challenges of daily life. Needs arise in contexts such as interpersonal relationships, family life, employment and education, and are shaped by the cultural context

of the individual's life, the meanings ascribed to the condition and by religious or spiritual beliefs. The intensity of need can vary from intermittent mild concern to persistent high levels of distress that may result in unpleasant physiological symptoms, low mood, loss of motivation, eating disturbances and inadequate self-care.

Some people with diabetes have psychological needs that do not meet the criteria for a formal diagnosis. Despite not meriting a diagnosis as such these needs can still have a significant impact on wellbeing and the ability of an individual to self-manage their condition.

There is however considerable evidence, reported in sections 2 and 5, that there is an elevated prevalence in people with diabetes of psychological distress that meets the criteria for a formal diagnosis. Depression, anxiety and disordered eating are associated with sub-optimal diabetes control, a reduction in the capacity to self-manage and the development of inappropriate self-care behaviours.

The notion of a continuum is helpful when thinking about psychological need and the types of interventions that might be appropriate. The continuum includes everyone from those who are coping well to those with psychiatric conditions. Crucially, it encompasses the large population of people with diabetes who do not meet the criteria for a formal diagnosis but whom nonetheless experience levels of distress and symptoms sufficient to adversely affect self-management and quality of life. At the other extreme, people with more complex mental illness such as schizophrenia, and related psychotic disorders, bipolar affective disorder, severe or chronic, recurrent depression or eating disorders are likely to have more complex needs, in some cases exacerbated by social exclusion, which require more substantial support to enable them to manage their diabetes

²² Clement (1995)

²³ Tankova et al (2004)

²⁴ Hawthorne and Tomlinson (1997)

appropriately. This group is probably larger than previously thought as people with severe mental illness have a greater risk of diabetes than the general population. For instance, the prevalence of diabetes in people with schizophrenia is 15 per cent compared to the 4-5 per cent in the general population.²⁵

The pyramid model

The Pyramid of Psychological Problems²⁶ (Figure 2.1) can be used to conceptualise the range of psychological needs present in any population or, over time, in any individual. The model describes an increasing complexity and severity of emotional and psychological difficulties,²⁷ which is based upon a quantitative and qualitative description of the distribution of these problems. This model provides a framework for commissioners who will need to verify the needs of their local population via a local health needs assessment. From a population perspective, this framework can be used to describe differences in need against differences in variables such as type of diabetes, duration of the condition, lifespan, and socio-demographic characteristics.

The boundaries between the levels of the pyramid are not absolute, and there may be some overlap between the different levels. From an individual perspective, it is important to retain the concept of the dynamic fluctuation of need that may occur over time. Needs vary with different stages of life

and with time spent living with diabetes, and may intensify during important life changes such as transition, pregnancy or the development of medical complications. The needs of family members or other carers can also be articulated against this model.

There is potential for the model, as illustrated, to be integrated into diabetes services or the stepped care framework of the Improving Access to Psychological Therapies (IAPT) programme. However emotional and psychological care ought to be embedded in healthcare systems as an integral part of all diabetes care pathways, regardless of organisational boundaries.

The diversity of mental health and diabetes competences required of healthcare professionals, to detect and offer early treatment or signposting where necessary, necessitates close co-working between diabetes and mental health services especially for children and young people and their families and carers where any model of care needs to be integrated to ensure rapid assessment and intervention. In many cases the child may require services and input from different levels at the same time.²⁸ Further details of workforce planning and competences are outlined in section 7.

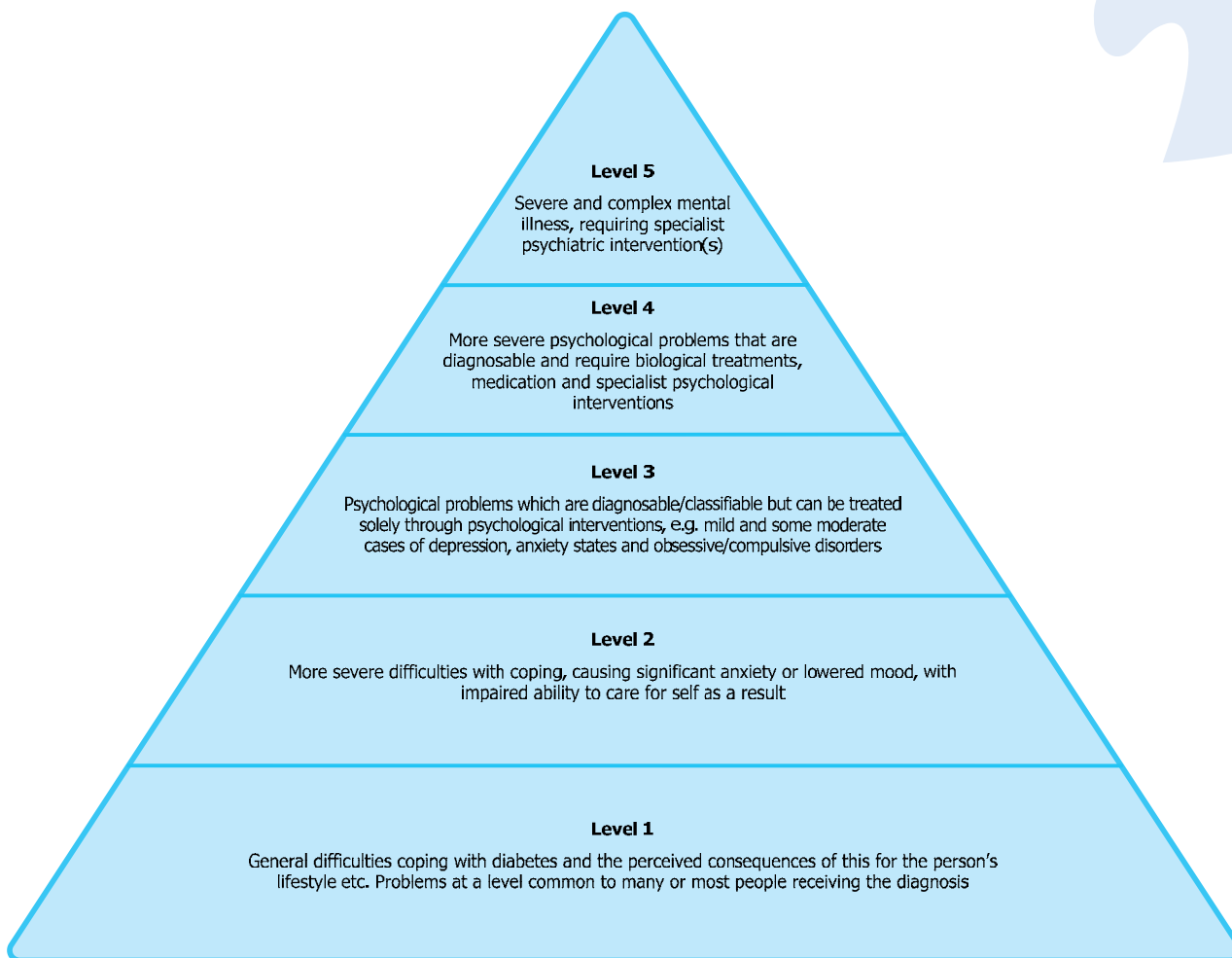
²⁵ Dixon L, Weiden P, Delahant J, et al (2000)

²⁶ Trigwell et al (2008)

²⁷ The five level pyramid was developed for the National Survey of Psychological Services for People with Diabetes commissioned by Diabetes UK. Although the final publication (Trigwell et al 2008) presented a three level model, the original five levels have been retained in this document to allow more detailed descriptions of the emotional and psychological issues concerning people living with diabetes.

²⁸ Department of Children, Schools and Families (2008)

Figure 2.1 Pyramid of psychological problems



Evidence supporting the pyramid model

The following is a summary of the literature describing the range of emotional and psychological needs of people with diabetes, structured according to the five levels of the pyramid model described above.

Level 1

Level 1 is associated with general difficulties coping with diagnosis, the day-to-day reality of living with diabetes and its perceived consequences.

Compared to the general population, people with diabetes have elevated rates of stress, poorer emotional adjustment and worse quality of life.²⁹ It is estimated that approximately 60 per cent of adults with either Type 1 or 2 diabetes report at

least one troublesome emotional concern related to diabetes.³⁰ Common concerns amongst adults include:³¹

- feeling scared and angry about having the condition
- worry about the future consequences of the condition
- feelings of guilt and anxiety associated with setbacks in self-management
- feeling deprived of food and constantly concerned about eating
- resentment of the pain and inconvenience associated with self-monitoring blood glucose and injecting
- resentment of the impact of diabetes for the rest of one's life and that it is always there-the '24-7' (every hour-every day) phenomenon

²⁹ Rubin and Peyrot (1999), Chouhan and Vyas (2006)

³⁰ Polonsky et al (1995)

³¹ Polonsky et al (1995), Beeney et al (1996), Welch et al (1997), Snoek et al (2000), Rubin and Peyrot (2001), Cai-Xia et al (2006), Delahanty et al (2007)

- frustration at unpredictable and high blood glucose levels
- fear associated with beginning insulin therapy, feeling that this will complicate life, cause hypoglycaemia, and represent a worsening of the condition and a personal failure to self-manage.
- fear of hypoglycaemia³²
- unhappiness with the patient-health professional relationship³³

Children and adolescents with diabetes share many of the concerns and anxieties as adults with diabetes. There is, however, specific evidence that they may also:

- fear injections and episodes of ketoacidosis³⁴
- feel different to their peers, ultimately threatening their concept of self³⁵
- resent the impact on school attendance and functioning³⁶
- report emotional problems relating to perceived parenting stress, family conflict³⁷ and the demands of assuming responsibility for self management as they grow older³⁸
- resent the restrictions on eating as freely as their peers
- develop time of onset weight concerns, eating problems and disorders⁴⁰

Level 2

The presenting issues at level 2 are less prevalent than those at level 1 and include more severe difficulties coping, causing greater anxiety or lowered mood, with impaired ability to self-care as a result.

General and diabetes-related chronic stress at level 1 can lead to symptoms of anxiety and depression

at level 2.⁴¹ People may be struggling emotionally with diabetes-specific issues without meeting the criteria for a diagnosable clinical condition. People with Type 1 diabetes describe feeling psychologically low,⁴² and children with Type 1 diabetes report more symptoms of anxiety and depression than those without the condition, although this may not lead to a diagnosis of depression or anxiety disorders.⁴³

Level 3

Emotional and psychological needs at level 3 are defined by psychological conditions that are diagnosable and can generally be treated through psychological intervention alone. These include mild and some moderate cases of depression, anxiety states and obsessive-compulsive disorders, and disordered attitudes to eating and/or eating behaviours.

Insulin therapy and some oral hypoglycaemic agents are associated with weight gain that may contribute to negative body image (particularly in females) and weight management problems. In adolescents non-deliberate or deliberate insulin omission can be a common issue.⁴⁴

In a condition with such an emphasis on food and dietary management, it is no surprise that disordered eating behaviours are very prevalent, are frequently accepted as typical and so are not given appropriate clinical attention. Eating disorders include anorexia, bulimia and Eating Disorder Not Otherwise Specified, (EDNOS). EDNOS includes symptoms that do not meet the criteria for diagnosis for anorexia or bulimia eating disorder such as insulin omission to manage weight, or binge eating without purging.

³² Wild D et al (2007)

³³ Ciechanowski PS, Katon WJ, Russo JE, Walker EA (2001).

³⁴ Johnson (1980)

³⁵ Dovey-Pearce et al (2007)

³⁶ dos Santos (2003), Allan et al (2008)

³⁷ Weinger et al (2001), Piazza-Waggoner et al (2008)

³⁸ Fleming et al (2002)

³⁹ Jones et al (2000), Nielsen (2002)

⁴⁰ Rydall et al (1997), Jones et al (2000), Maharaj et al (2003)

⁴¹ Peyrot and Rubin (1997), Fisher et al (2001), Pouwer et al (2005), Hermanns et al (2006)

⁴² Tierney et al (2008)

⁴³ Moussa et al (2005)

⁴⁴ Weissberg-Benchell J et al (1995)

Eating disorders are twice as prevalent in young women with Type 1 diabetes compared to the healthy female adolescent population⁴⁵ and are found in between 14 and 34 per cent of female adolescents and young adults with Type 1 diabetes.⁴⁶ The prevalence of eating disorders amongst women with Type 2 diabetes is 21 per cent.⁴⁷

Level 4

Emotional and psychological needs at level 4 are defined by psychological problems that are less prevalent but more severe than at level 3. These problems are diagnosable and require biological, medication and/or specialist psychological intervention.

Level 4 includes major depression diagnosed by a standardised, structured diagnostic interview. People with diabetes are twice as likely to have clinical depression at this level compared to the general adult population, irrespective of the type of diabetes,⁴⁸ with prevalence between six and fourteen per cent at this level.⁴⁹

Severe anxiety disorders affect 14 per cent of adults with diabetes.⁵⁰ Disordered eating, usually diagnosed as bulimia nervosa, is at least twice as common among adolescent females with Type 1 diabetes than in the general population⁵¹ with prevalence ranging from 10 to 28 per cent.

Level 5

Level 5 covers mental illness requiring specialist psychiatric intervention. This could include severe cases of depression or eating disorders, as well as conditions usually referred to as severe mental illness (SMI). While this is probably the least prevalent of emotional and psychological need, the problem is often complex. Type 2 diabetes is at least twice as common in adults with schizophrenia or schizoaffective disorder as in the

healthy population, especially in young adults.⁵² Prevalence estimates have ranged from 9 to 16 per cent. This increased prevalence is partly attributable to weight gain associated with second generation, atypical anti-psychotic medications.⁵³ Schizophrenia may predispose individuals to Type 2 diabetes due to increased stress, a sedentary lifestyle, poor diet and high BMI.⁵⁴ Co-morbidity of Type 2 diabetes is also documented in other psychiatric conditions, namely dementia and bipolar disorder, with prevalence estimates of 18 and 26 per cent respectively. The latter is significantly greater than that in the general population.⁵⁵

Summary

This evidence base broadly supports the pyramid model in terms of both the scale and the severity of need at each level: the prevalence of emotional and psychological need reduces, while severity increases, from level 1 to level 5. People may simultaneously have needs represented at several levels, for example, an individual with a severe mental health issue at level 4 may also have a level 1 anxiety surrounding an aspect of their diabetes management. Prevalence is around 60 per cent at level 1, 40 per cent at level 2, 20-30 per cent at level 3, and 10-15 per cent at levels 4 and 5. Any individual may move up or down these levels at different point in his or her life, depending on personal circumstances and the scope and nature of the effects of diabetes. Psychological distress may be linked to the challenges of living with diabetes or it may be caused by other reasons entirely. Either way, wellbeing suffers and the self-management of diabetes on a daily basis can in turn be undermined. Further models of care are described in Appendix B.

⁴⁵ Jones et al (2000), Nielsen (2002)

⁴⁶ Rydall et al (1997), Jones et al (2000), Maharaj et al (2003)

⁴⁷ Kenardy et al (2001)

⁴⁸ Anderson et al (2001)

⁴⁹ Fisher et al (2007), Pibernik-Okanovic et al (2008), Lloyd et al (2000), Shaban et al (2006), Collins et al (2009), Gavard et al (1993), Hermanns et al (2006)

⁵⁰ Grigsby et al (2002)

⁵¹ Jones et al (2000), Nielsen (2002)

⁵² Rouillon and Sorbara (2005), Cohen et al (2006)

⁵³ Smith M, Hopkins D, Peveler RC et al (2008)

⁵⁴ Regenold et al (2002)

⁵⁵ Regenold et al (2002)

Case Study 1: Salford

Diabetes and common mental health problems: the Salford experiment

Background

With the advent of the Improving Access to Psychological Therapies (IAPT) programme, Salford Primary Care Trust became a Pathfinder site, one of the first 10 places in England to expand psychological therapies in primary care. Diabetes was identified as a special interest. This was partly borne out of an increasing interest within the primary care mental health team in the high prevalence of co-morbid diabetes and depression and the research interests of the psychiatrist and team leader. The team approached contacts in the primary care trust and the local acute trust and, with their help and the enthusiastic support of the primary care trust diabetes team, set about co-designing a care pathway.

The initial focus was on the mental health needs of people with Type 1 diabetes, of whom there are approximately 1000 on the register in Salford. Everyone on the register was sent a copy of the Diabetes UK publication on diabetes and depression, two screening instruments that are being used in the IAPT programme (the PHQ-9 for depression and the GAD-7 for anxiety) with a covering letter and invitation to discuss the issues further with the consultant.

Services provided

The initial project is now nearing completion. Those who responded with high scores on the screening instruments were offered an appointment at the primary care trust diabetes clinic with a mental health worker trained in brief psychological interventions and medication management. All others have been invited to come in and see the nurse specialist to discuss their needs, with possible referral through to the DAFNE programme running in the primary care trust. Through this process we have identified several people with moderate to severe depression who have clearly been receiving suboptimal depression treatment from their GP and who were either not engaging successfully with the diabetes services and/or having problems with their diabetes self-care. Some have been referred, with our support, to more intensive treatment within the mental health service.

We now have a mental health worker on-site in the diabetes clinic for one session per week, taking referrals directly from the diabetes team. Supervision and consultation is provided but we are aware that a) we need greater capacity within the service and b) some specialist psychological input from a cognitive behavioural therapist or psychologist familiar with the particular problems associated with diabetes is needed in order to provide a more effective 'stepped care pathway'.

Factors underpinning success:

- Close working relationship between services
- Psychological therapy provided on-site, facilitating joint working
- Joint team meeting and mutual opportunities for training
- Support of the local consultant diabetologist and diabetes forum.

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3. Policy context

The importance of responding appropriately and effectively to the emotional and psychological needs of people with diabetes is highlighted in a wide range of national policy documents. This section describes relevant policy and programmes and summarises specific recommendations made about the role of emotional and psychological care both for people with diabetes, carers and families and for the population as a whole.

The National Service Framework for Diabetes

The diabetes National Service Framework⁵⁶ recognises the significant psychological impact of diabetes and the need for emotional and psychological services to ensure that people with diabetes are supported to self-manage effectively.

Standard 3

“All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.”

Standard 5

“All children and young people with diabetes will receive consistently high-quality care and they, with their families and others involved in their day-to-day care, will be supported to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development.”

Standards 10 - 12

The aim of these standards is to “minimise the impact of the long term complications of diabetes by early detection and effective treatment and by

maximising the quality of life of those who develop the long term complications”. This includes the need for regular surveillance and effective management of conditions, such as depression, that more commonly occur in people with diabetes, to reduce the impact these have on people with diabetes.

The Children’s National Service Framework

The National Service Framework for children, young people and maternity services⁵⁷ recognises that emotional needs form an important part of the overall needs of children and young people:

Standard 6

“All children and young people who are ill, or thought to be ill, or impaired, will have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness”.

Standard 8

“Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family centred services which are based on assessed needs, which promote social inclusion and where possible, which enable them and their families to live ordinary lives”.

The National Service Framework for Renal Services

Nephropathy is a complication of diabetes. The National Service Framework for renal services⁵⁸ outlines care pathway for people with chronic kidney disease and those undergoing renal replacement therapy which include psychological and social support for people with diabetes and carers. Referral to a multi-skilled team for

⁵⁶ Department of Health (2001a)

⁵⁷ Department of Health (2004a)

⁵⁸ Department of Health (2004b)

psychological preparation prior to dialysis, or if transplant fails, is highlighted as a marker of good practice under Standard 2 of the framework.

The National Service Framework for Older People

Standard 7 of the National Service Framework for older people states:⁵⁹

“Older people who have mental health problems have access to integrated mental health services, provided by the National Health Service and councils to ensure effective diagnosis, treatment and support, for them and for their carers.” The framework recognises that mental and physical conditions can interact to complicate the assessment and management of the care of older people.

The guidance goes on to state, “Mental health services for older people should be able to respond effectively to individual needs, and take account of the social and cultural factors affecting recovery and support.”

The National Service Framework for Long Term Conditions

The National Service Framework for long term conditions⁶⁰ recognises the impact that living with a long term condition can have on the emotional wellbeing of individuals and their carers. It specifies that people with long term conditions should have an integrated assessment, including assessment of psychological and emotional difficulties, and access to emotional and psychological support and services. Psychologists are considered part of the multidisciplinary team.

New Horizons: A shared vision for mental health

New Horizons⁶¹ is a cross government action programme that builds on the mental health National Service Framework which has been in place for a decade. The document identifies key areas requiring action to improve mental health,

recognising what is already being undertaken across government to achieve this and the commitments of government departments to this end. The key themes of care identified, which are common to those for people with long term conditions, include; personalised care, multi agency commissioning and collaboration, prevention, early intervention and the promotion of mental wellbeing. The need to tackle the discrimination and inequalities experienced by people with mental health conditions in accessing services is also highlighted.

Our Health, Our Care, Our Say

Maintaining the emotional wellbeing and mental health of the population is one of the four main aims of the white paper, *Our Health, Our Care, Our Say: a new direction for community services*.⁶² The document highlights the loss of quality of life and productivity resulting from poor emotional wellbeing, and the positive impact that promoting emotional wellbeing can have. Treatment choice and the role of ‘talking therapies’ are emphasised with a commitment to increase access to psychological therapies. The role of primary care in the provision of support for people with mild to moderate mental health problems is emphasised together with recommendations for how this can be taken forward.

High Quality Care for All: NHS next stage review final report

Lord Darzi’s report⁶³ emphasises the significance of mental wellbeing and mental health promotion. Mental wellbeing is seen as one of six key goals for ‘staying healthy’.

Partly in response to Lord Darzi’s recommendations, Healthcare for London has recently developed a diabetes guide for London.⁶⁴ The guide recognises the significance of emotional and psychological wellbeing as an aspect of diabetes care and the importance of incorporating this care into diabetes services.

⁵⁹ Department of Health (2001b)

⁶⁰ Department of Health (2005a)

⁶¹ Department of Health and HM Government (2009a)

⁶² Department of Health (2006)

⁶³ Professor the Lord Darzi of Denham (2008)

⁶⁴ Healthcare for London (2008)

NHS Operating Framework and public service agreement targets

The early identification of mental health issues and the provision of psychological therapies for people with mild to moderate depression and anxiety are identified within the NHS operating framework.⁶⁵

Public service agreements⁶⁶ (PSAs), included within the National Health Service operating framework's 'vital signs', define the Government's highest priority outcomes. The public service agreement targets, and their indicators, include a number that are relevant to the emotional wellbeing of people with diabetes.

PSA 12 - to improve the health and well being of children and young people

Indicator 4 relates to the emotional health and wellbeing of children and the performance of child and adolescent mental health services. The indicator is expressed within Vital Signs as: "Effectiveness of Children and Adult Mental Health Service (CAMHS) (percentage of Primary Care Trusts and local authorities that are providing a comprehensive CAMHS)" and is a national priority for local delivery.

PSA 18 – to promote better health and wellbeing for all

Indicator 5 relates to access to psychological therapies: "the proportion of people with depression and/or anxiety disorders who are offered psychological therapies".

PSA 19 - to ensure better care for all

Indicator 5 relates to supporting people with long term conditions to self-manage: "People with long term conditions supported to be independent and in control of their condition".

The NHS Constitution

The NHS Constitution⁶⁷ sets out the principles and values of the NHS in England, identifying the rights and responsibilities of the person with diabetes, public and staff. It highlights the role of the NHS in keeping the population in good mental as well as physical health.

"It is there to improve our health and wellbeing, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives."

Making Every Young Person with Diabetes Matter

This report by the Department of Health's children and young people with diabetes working group⁶⁸ highlights the need for the integration of psychological support in diabetes service provision. It recommends a competence-based approach to workforce that includes psychology and psychological support, and that mental health and emotional wellbeing form part of the recommended service specification for diabetes care for children and young people.

"The local diabetes services will need to provide access to routine and integrated psychological support and local counselling."

Every Child Matters

Every Child Matters⁶⁹ informed the Children Act 2004 which provides legislative support for the development of integrated, effective and accessible services that are centred on the needs of children, young people and their families. The Government's aim is for every child to be given the support they need to:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic wellbeing

Supporting and promoting the psychological wellbeing of children and young people is encompassed within the Every Child Matters Green Paper and the subsequent Outcomes Framework. Public Service Agreements and National Indicators have been developed that relate to the mental wellbeing of children and young people.⁷⁰

⁶⁵ Department of Health (2008)

⁶⁶ HM Treasury (2009)

⁶⁷ Department of Health (2009c)

⁶⁸ Department of Health (2007a)

⁶⁹ Department of Children, Schools and Families (2003)

⁷⁰ Department of Children, Schools and Families (2008)

Healthy Lives, Brighter Futures – the strategy for children and young people’s health

The national child health strategy⁷¹ emphasises the importance of emotional wellbeing for children and young people and, in particular, the importance of care for children and young people with additional health needs: “Ensuring that services are of high quality and are responsive to the needs and expectations of those who use them is especially important when children and young people have acute or additional health needs”.

Building on the 2008 review of child and adolescent mental health services (CAMHS), work is underway to develop stronger commissioning of the CAMHS pathway. In addition work continues in the Improving Access to Psychological Therapies programme (IAPT), with pathfinder sites that have a specific focus on children and young people.

Delivering Race Equality in Mental Health Care

The Department of Health has developed this five year action plan⁷² in recognition of the inequalities people from Black, Asian and minority ethnic communities can experience in their access to, and experience of, mental health services. The foundations of this action plan include developing more appropriate and responsive services, a culturally competent workforce, community engagement and better information both about and for mental health service users.

Generic Choice Model for Long Term Conditions

This Department of Health document⁷³ outlines the significance of personalised services for people with long term conditions. This is achieved via a care planning process that helps identify an individual’s needs including emotional and psychological support or care. The importance and need for a range of choices to meet psychological need is also identified.

Year of Care Programme and the care planning approach

The Year of Care pilot programme,⁷⁴ undertaken by the Department of Health, Diabetes UK, NHS Diabetes and The Health Foundation, describes the ongoing care a person with diabetes can expect to receive in a year which can be costed and commissioned. It uses the collaborative care planning approach to consultations between healthcare professionals and people with diabetes to support people to identify their needs and goals. The ways in which people can be supported to meet these goals, and effectively self-manage, are then agreed in partnership. These may involve individual actions and service actions.

This information is then used to inform population-level (macro-) commissioning.

World Class Commissioning

World Class Commissioning is a programme of work led by the Department of Health which aims to ensure high quality commissioning of health and social care services in the NHS.⁷⁵ Eleven competences have been developed. These include the need for commissioners to:

- Work in partnership with local bodies and communities to help stimulate innovation and encourage better service design.
- Undertake robust and regular needs assessments, prioritising investment according to local need, to help address the greatest health inequalities.
- Involve the patients, their carers, the public, clinicians in the commissioning process.

NHS Diabetes Commissioning Guide

The NHS Diabetes Commissioning Guide⁷⁶ describes an approach to commissioning services that ensures that people with diabetes have access to emotional and psychological support as part of their initial assessment and ongoing care as well as in the management of psychological complications.

⁷¹ Department of Health (2009d)

⁷² Department of Health (2005b)

⁷³ Department of Health (2007b)

⁷⁴ www.diabetes.org.uk/Guide-to-diabetes/Year-of-care

⁷⁵ http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/DH_083197

⁷⁶ NHS Diabetes (2009)

According to the guide, markers of best practice in the commissioning of diabetes services include the provision of support and psychological services, the achievement of Quality Outcomes Framework indicators and National Service Framework standards, and the establishment of an agreed local pathway to follow up people with diabetes diagnosed with depression.

The Quality Outcomes Framework indicators⁷⁷ for depression can provide commissioners with evidence, alongside local audits, of improvement in this area. Relevant indicators are:

- *DEP 1*: The percentage of patients on the diabetes register and/or the CHD register for whom case finding for depression has been undertaken on one occasion during the previous 15 months using two standard screening questions.
- *DEP 2*: In those patients with a new diagnosis of depression, recorded between the preceding 1 April to 31 March, the percentage of patients who have had an assessment of severity at the outset of treatment using an assessment tool validated for use in primary care.

- *DEP 3*: In those patients with a new diagnosis of depression and assessment of severity recorded between the preceding 1 April to 31 March, the percentage of patients who have had a further assessment of severity 5 – 12 weeks (inclusive) after the initial recording of the assessment of severity. Both assessments should be completed using an assessment tool validated for use in primary care.

Key Performance Measures are currently being developed as part of the commissioning guide. These will be under constant review and it is anticipated that the measures will indicate clinical quality, patient experience and engagement through clinical outcomes and patient feedback or process measures. Many measures are already in place through the existing system, but to assess quality effectively, all aspects of quality must be evaluated.

⁷⁷ British Medical Association and NHS Employers (2009)

Case Study 2: Tower Hamlets

Clinical Health Psychology Service

Background

A full time clinical psychologist provides direct clinical care in partnership with diabetes multidisciplinary team members for people with diabetes from the age of transfer to adult services (between 16 – 20 years) and upwards. Family members and professional carers can also be seen by the service. The clinical psychologist also provides training and supervision sessions for multidisciplinary team members. The clinical psychologist gained their knowledge in diabetes through research, working with the multidisciplinary team and attending the structured education courses for people with Type 1 and Type 2 diabetes.

Services provided

The clinical psychology service is advertised via leaflets in English and Bengali. People with diabetes can self refer or ask for a referral from a member of the diabetes service, GP or mental health professional.

A weekly assessment clinic is held at the Diabetes Centre where the psychologist and individual can meet to discuss the service and agree a timescale if it is still wanted. Decisions about the Type and duration of support offered depend on the needs of the individual. One to one and family based sessions are offered.

The psychologist offers a 10 week Mindfulness for *People Living with Diabetes Group* twice a year. Mindfulness supports people to develop their own meditation practice. Mindfulness has been shown to reduce stress and low mood and help people cope with pain. People with diabetes often find it helps them accept their condition and offers a chance for a gentler attitude towards self-care. This innovative mindfulness group is the focus of ongoing research.

The psychologist offers two support group meetings a year for young people under 35 and an insulin pump users group is also planned which will be run jointly by the psychologist, diabetes specialist nurse and dietitian. The psychologist also attends the local structured education courses for people with Type 1 and Type 2 diabetes in order to explore wellbeing issues with attendees and to highlight the clinical psychology service.

The service is evaluated using patient satisfaction questionnaires, focus group work, and standardised outcome measure tools. In addition, improvements to self-care are measured using biomedical outcome measures such as HbA1c, as well as other behavioural outcomes.

As well as providing direct clinical care, the clinical psychologist offers training and consultation to members of the multidisciplinary diabetes team and to other professionals. The psychologist also provides group supervision for the diabetes team and individual supervision for the diabetes specialist nurses.

Factors underpinning success

The psychologist works closely with the multidisciplinary team, attending monthly clinical team meetings, and business meetings. The service is flexible and person-centred and responds to service users' feedback (for example the young people's support group has been scaled back from monthly to twice a year following participant feedback). The service is easily accessible for people with diabetes who can self refer and need not inform their GP.

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NICE guidance

The National Institute of Health and Clinical Excellence (NICE) has developed guidance⁷⁸ focused on mental wellbeing and on the management of diabetes. These span clinical guidelines, technology appraisals, interventional procedures and public health guidance. Some of these documents are of relevance to the provision of emotional and psychological care and support for people with diabetes. Furthermore, some of the guidelines developed for the identification and management of psychological conditions, for example the schizophrenia guideline,⁷⁹ contain recommendations relating to awareness and identification of diabetes, and ensuring appropriate diabetes care is provided in line with the relevant clinical guidelines.

Clinical guidelines for the management of Type 1 and Type 2 diabetes

The clinical guidelines for the management of Type 1⁸⁰ and Type 2⁸¹ diabetes contain a number of relevant points including (paraphrased):

- ‘Multidisciplinary teams (MDTs) should be alert to the development or presence of clinical or subclinical depression and/or anxiety, especially if there are problems with self-management.’⁸⁰
- Diabetes professionals should be ‘able to detect and basically manage non-severe psychological disorders in people from different cultural backgrounds.’⁸⁰
- Diabetes professionals should be ‘familiar with counselling techniques and drug therapy, while arranging prompt referral to specialists, especially if there is significant interference with wellbeing or diabetes self-management.’⁸⁰
- Diabetes professionals should be ‘alert to eating disorders and insulin dose manipulation if there is either poor glucose control, low BMI or over concern with body shape and weight. Early, and occasionally urgent, referral to local eating disorder services should be considered.’⁸⁰
- “The aims of structured education and self-management programmes are to improve outcomes through addressing the individual’s health beliefs, optimising metabolic control,

addressing cardiovascular risk factors (helping to reduce the risk of complications), facilitating behaviour change (such as increased physical activity), improving quality of life and reducing depression.”⁸¹

- People with Type 2 diabetes with psychological and/or depressive disorders should be identified by continuing professional awareness, and managed in accordance with current national guidelines.’⁸¹

Clinical guidelines for depression in adults with chronic physical health problems⁸²

These guidelines acknowledge the elevated rates of depression among people with long term conditions, the relationship between these, and the clinical, quality of life and financial costs of depression.

The guidelines emphasise the value of both the stepped care approach and collaborative care model. The stepped care approach (see Appendix B) describes the “stepping up” of the intensity of treatment in accordance with review of an individual’s need and the efficacy of the intervention they are currently receiving. The characteristics of the collaborative care model include:

- collaborative definition of problems, identified by both individuals and their healthcare professional
- joint care planning and goal setting in line with a person’s readiness and choices
- access to supported self-management including emotional support
- regular review and updating of the care plan

The guidelines recommend the following interventions to manage depression:

- peer support
- psychological therapies and interventions
- pharmacological therapies

Public Health guidance for promoting young people’s social and emotional wellbeing in secondary education⁸³

This guidance is primarily aimed at those who have a direct or indirect role in the emotional wellbeing of young people in secondary education settings, including; local authorities, the NHS and the wider

⁷⁸ See www.nice.org.uk/guidance

⁷⁹ See <http://guidance.nice.org.uk/CG82>

⁸⁰ See <http://guidance.nice.org.uk/CG15>

⁸¹ See <http://guidance.nice.org.uk/CG66>

⁸² See <http://guidance.nice.org.uk/CG91>

⁸³ See <http://guidance.nice.org.uk/PH20>

public, voluntary and community sectors. The guidance explicitly recommends that practitioners working with young people have the "knowledge, understanding and skills they need to develop young people's social and emotional wellbeing. Training may cover...the issues in relation to different medical conditions (such as diabetes, asthma and epilepsy) to ensure young people with these conditions are not bullied, inappropriately excluded from school activities or experience any undue emotional distress"

Improving Access to Psychological Therapies (IAPT) Programme

The IAPT programme⁸⁴ has been established to support Primary Care Trusts in implementing NICE guidance for depression and anxiety by providing rapid access to NICE approved interventions including Collaborative Care. Collaborative Care is an evidenced based model of care designed specifically for people with depression who also have a long term physical condition such as diabetes. More information can be found at www.iapt.nhs.uk. Outcomes from the pilot sites include improvements in health and wellbeing and improved access to services.

No Health Without Mental Health

The Royal College of Psychiatrists and the Academy of Medical Royal Colleges have developed a framework⁸⁵ to support improvement in general hospital settings. This framework acknowledges the importance of raising awareness of the links between mental and physical health, improving the mental healthcare provided to individuals with physical health needs and improving the physical health care provided to people with mental health conditions. The report identifies:

- The need to raise awareness of the increased risk people with learning disabilities have of developing particular health conditions.
- The need for education and training in mental health for healthcare professionals.
- The need for the service user to be involved in designing services and to be supported in the management of their condition.

- The need to commission flexible liaison psychiatry services.

Healthy Mind, Healthy Body

The briefing paper from the NHS Confederation⁸⁶ identifies the importance of integrating the provision of physical and mental healthcare and acknowledges the increased prevalence of mental health needs amongst people with physical health conditions. In particular the paper recognises the role that liaison psychiatry services can play in improving quality and productivity in inpatient settings.

The paper cites evidence indicating that the identification and treatment of the mental health needs of hospital inpatients has a positive impact on their recovery and their physical wellbeing. Service models such as liaison psychiatry are seen as effective ways of addressing individual mental health needs and thereby reducing costs linked to length of hospital stay and rates of re-attendance and re-admission. The liaison team is also seen as a source of support and training for other colleagues.

Conclusion

People with diabetes access support from a range of sources including family, friends, peers and service providers. Emotional and psychological services are valued as integral parts of the National Health Service, meeting needs that are widely acknowledged to underpin everyday life.

The breadth of national policy reflects the importance of emotional and psychological services in addressing differences in need across the stages of an individual's life and differences in need across the diversity of population subgroups, however these may be defined. People with diabetes have characteristic emotional and psychological needs and a shared experience of related illness. However, every person with diabetes is also an individual with individual needs.

National policy points towards an approach to providing emotional and psychological services, integrated with diabetes services that recognise the needs of the group while also responding to the needs of the individual.

⁸⁴ See www.iapt.nhs.uk

⁸⁵ Academy of Medical Royal Colleges (2009)

⁸⁶ NHS Confederation (2009)

Case Study 3: University College London

University College London Hospital

Background

At University College London Hospital (UCLH), psychological care is an important part of the overall care that children and adolescents receive. The paediatric and adolescent psychological services work as part of the clinical team looking after children and young people who are either an in patient or attending an out patient clinic under the care of a UCLH paediatrician.

The psychological services team consists of clinical psychologists, psychotherapists and psychiatrists. The service contributes to a range of specialist multidisciplinary programmes for children and adolescents with cancer and other long term chronic health conditions including management of complex chronic fatigue and chronic pain syndromes, an award winning weight management programme and a nationally recognised service for children, young people and families living with diabetes.

Diabetes specific services

Psychological services are an integrated component of the paediatric and adolescent diabetes service. All members of the psychology team attend the basic and advanced diabetes study days. The consultant clinical psychologist that attends the diabetes multidisciplinary team meetings is a certified diabetes pump trainer and attends the yearly American Diabetes Association Postgraduate update training meetings.

The diabetes service currently has a case load of 250 children and young people aged from birth to nineteen years. Forty per cent are currently on pumps. Regular audit has demonstrated high levels of satisfaction with the service with over fifty per cent of the case load having had an opportunity to meet with members of the psychology team.¹

Reasons for referrals include: a) discussing the impact of diagnosis on the family; b) specific support for managing needle phobia; c) managing the impact of diabetes at different developmental stages; and d) addressing difficulties associated with poor control.

A range of psychological approaches are offered for individuals and families. The team works within a systemic framework and offers solution-focussed, narrative and motivational interviewing as well as cognitive behavioural therapy.²

Where families are unwilling or unable to accept an invitation to meet with a member of the psychology team, we provide consultation to the diabetes team, including case discussion and supervision. For complex cases, network meetings are arranged in order to invite members of the diabetes team, the family and other members of the network to join together to think about how to agree shared management plans.

The psychology service takes an active role in professional development and clinical research as part of the team.³ Members of the psychology team are regular presenters at training workshops for doctors, nursing teams and school teachers and contribute to regular pump education update days for young people and families.⁴

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¹ Christie D et al (2003), Christie D et al (2008)

² Christie D (2007), Christie D (2008)

³ Christie D et al (2009), Viner RM et al (2003)

⁴ Thompson R et al (2003)

4. Current provision

People with diabetes have significant emotional and psychological needs which can profoundly affect daily self-care. Yet, as the evidence in this section demonstrates, current service provision in the UK falls far short of meeting these needs. There are many pockets of good practice but worrying gaps exist in the provision of emotional and psychological care services. For some people with diabetes, this limited access is compounded by wider health inequalities.

In order to establish a clear picture of the level and nature of psychological support provided for people with diabetes, the *Minding the Gap* survey,⁸⁷ undertaken by professionals in partnership with Diabetes UK, examined all secondary care diabetes services in the UK. The survey focused on provision for people with diabetes aged 17 and over. The Talking Diabetes DEPICTED study has explored the provision of psychosocial support in paediatric diabetes services.⁸⁸

Minding the Gap

The gap described by *Minding the Gap* falls between the current state of service provision and the level that needs to be commissioned. Only 32 per cent of diabetes services have access to specialist psychological service provision and only 25 per cent can name and give contact details for a person providing such a service. Of this 25 per cent, 58 per cent offer a dedicated psychological service rather than simply access to a local generic psychological service. Thus 85 per cent of people with diabetes in the UK have either no defined access to psychological support and care, or at best access to a local generic mental health service.

The standards set out within the National Service Framework and the guidelines published by NICE provide a clear statement of the level and quality of services that people with diabetes ought to expect. Yet less than three per cent of diabetes services meet all six psychologically-relevant NICE

recommendations and National Service Framework standards, and 26 per cent do not meet any.

Where psychological services do exist they are provided by people from a range of disciplines, with psychologists the provider in 57 per cent of cases and liaison psychiatrists in 18 per cent of cases. There is no clear rationale for why services have developed in this manner; provision appears to be related to factors such as whether or not diabetes is a special interest of the provider. It is vital that service development is genuinely needs-led, planned and organised with workforce skills specified to match identified needs.

Just over a third of services provide access to psychological care on an urgent (same day) basis. Of the less urgent/routine cases provided for by specialist psychological services only 28 per cent see people with diabetes within a month of referral and 17 per cent have waiting times longer than three months.

Many diabetes teams do not have in place the basic components of care related to psychological need. Less than a third of teams have telephone advice systems that provide psychological support, around half have referral pathways to specialist teams for people with severe mental illness, over three quarters do not have protocols or guidelines for referring people with psychological needs of moderate severity and only one in ten has defined screening or assessment tools for psychological issues. Many multi disciplinary teams feel that they lack expert psychological input that is specific to, and integrated with, their interests as diabetes

providers. They want education, training and supervision, specialist help with eating disorders, and dedicated liaison psychiatry services. The presence of a psychological expert is associated with an increased likelihood that telephone advice systems, protocols for psychological issues and clear referral pathways will be in place.

⁸⁷ Trigwell et al (2008)

⁸⁸ Hamby H, Robling M et al (2009), DEPICTED Study Team (2006)

Case Study 4: Leeds Psychiatry

Leeds Liaison Psychiatry Service

Background

The Leeds Liaison Psychiatry team provides a mental health service to a number of general hospitals and specialities across the city. Services provided include:

- In-reach service to all medical and surgical wards, including Accident and Emergency services
- Specialist outpatient clinics
- Dedicated liaison psychiatry in patient unit
- Group treatment programme
- Sub-specialist elements including psychosexual medicine and psycho-oncology

Service provided to people with diabetes

The team has close links with the diabetes service. The liaison psychiatry team takes referrals from the diabetes centres of both large teaching hospitals in Leeds, and also from primary care. In 2008, 42 people with diabetes were referred to the outpatient service, 26 of whom were young people going through the transition from child to adult services. The range of needs addressed spanned classifiable conditions such as clinical depression, eating disorders and conditions that are not severe enough for a clinical diagnosis but still impact on individuals' emotional wellbeing and physical health. Motivational interviewing/enhancement is used with people who are having difficulty coping with their diabetes to help in dealing with the psychological aspects of their problems.

Characteristics underpinning success

The liaison psychiatry team has close working relationships with the diabetes centres in Leeds and with clinical psychology colleagues, characterised by regular and effective communication and shared care of patients. This helps provide an integrated service in which the different teams work closely together for the benefit of patients. This has been found to be particularly helpful in complex cases. Although no formal evaluation has been undertaken, feedback from people with diabetes and professional colleagues demonstrates the significant value placed upon the service which is seen to have a beneficial effect.

A shared care approach is adopted in working with people with diabetes and developing services to support them:

- The liaison psychiatry team provides support to diabetes team members, including case discussion and supervision.
- Visits by the diabetes team to the inpatient liaison psychiatry unit provide support regarding the physical aspects of diabetes care.
- The liaison psychiatry service was involved in service improvement and development, for example the development of a local transition service, in partnership with clinical psychology, paediatric and adult diabetology colleagues.

The liaison psychiatry service is working closely with the new clinical psychology service which will provide psychological support to people with diabetes in the community setting.

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Despite the lack of specialist input, 41 per cent of non-psychological diabetes team members have training in psychological therapies, suggesting an enthusiasm and interest in these aspects of diabetes care. However, diabetes teams feel they need help managing almost all psychological presentations and would like to have the opportunity to involve, or refer on to, specialist services for a range of conditions. It is vital that this need is recognised by commissioners.

According to *Minding the Gap* respondents, the three perceived gaps that are most pressing are:

- a need for increased resource allocation for psychological services for people with diabetes
- specific services for children and young people
- provision of diabetes-specific psychological services, integrated into current diabetes services

The DEPICTED study

The DEPICTED study (Development and Evaluation of a Psychosocial Intervention for Children and Teenagers Experiencing Diabetes) surveyed paediatric diabetes services. It found that most services were able to offer little psychological support to children and young people with diabetes, with an average of 1.9 sessions per month.⁸⁹

There is great variability in the type of psychosocial and educational interventions delivered. Although psychosocial issues are seen as important, professionals have significantly lower confidence in working with psychosocial issues compared to medical ones. Some practitioners do not feel able to address some psychosocial issues that are likely to be found in practice.

Professionals working within paediatric diabetes services had limited training in communication skills. Almost 25 per cent of nurses and 16 per cent of all doctors, nurses and dietitians had not received any training in communication skills, 47 per cent had received no training since graduation, and only 28 per cent had received specialist training such as motivational interviewing.⁹⁰

The findings demonstrate there is urgent need to establish models of care that meet the emotional and

psychological needs of children, young people and their families living with diabetes.

Diabetes UK research

Members' surveys

There were 15,885 responses to the 2009 Diabetes UK adult member's survey,⁹¹ 11 per cent of the adult (18 years and over) membership. Of these respondents, 42 per cent said that, in the 12 months prior to the survey, they would have liked to talk to someone about how they were feeling to help them cope with having diabetes.

Of those that wanted emotional support, 87 per cent wanted to talk to a healthcare professional as well as family and friends; 12 per cent wanted to talk to family, 10 per cent to friends and 9 per cent to a support group. Of those who wanted to speak to a healthcare professional, 74 per cent were able to do so.

A separate survey was sent to members aged 17 years and below and their families, of whom 661 responded (12 per cent). In the 12 months prior to the survey, 50 per cent of young people needed to talk to someone about coping with diabetes. In addition 35 per cent would like to be able to talk to a professional to help them cope with their diabetes whilst 83 per cent of those who wanted to, were able to. Young people identified access to professionals to talk about coping with diabetes as a priority for improving diabetes services.

Primary Care Organisations progress survey 2009

Of the Primary Care Trusts responding to this survey⁹², 60 per cent ensured provision of psychological support for adults aged over 16 years and 67 per cent ensured provision of psychological support services for children up to 16. In addition 80 per cent collated a list of local support organisations or voluntary groups, made these available via healthcare professionals to people with diabetes.

Policy forum

A Diabetes UK policy forum attended by people with diabetes, carers and healthcare professionals identified training and support for healthcare professionals, and the allocation of sufficient time for

⁸⁹ DEPICTED Study Team (2006)

⁹⁰ Hambly H, Robling M et al (2009)

⁹¹ Diabetes UK (2009a)

⁹² Diabetes UK (2009b)

consultations, as key requirements for the development of emotional and psychological support and care in diabetes services.⁹³ The forum delegates also recognised the valuable role of the support received from families, carers, friends and peers.

The National Patient Survey of People with Diabetes

This survey, conducted for the Healthcare Commission,⁹⁴ surveyed 68,501 people with diabetes in 2006. Three percent of survey respondents said that they needed to see a specialist for psychological help in relation to coping with their diabetes in the year prior to the survey. However only 53 per cent of those who said they needed this support received it. Sources of emotional support were identified as follows:

- Doctor at hospital (17 per cent)
- Doctor at GP surgery (16 per cent)
- Practice Nurse (11 per cent)
- Family or friends (10 per cent)
- Diabetes Specialist Nurse (4 per cent)
- Patient support group (3 per cent)
- Counsellor or telephone help line (1 per cent)

Survey of Psychological Services for People with Diabetes in the Transition Period

A survey was carried out in secondary care services across the Yorkshire and Humber Region during early 2009 to determine the availability of psychological support and care for young people with diabetes in the transition period (i.e. aged 16 to 25 years).⁹⁵

The survey questionnaire was developed in line with existing NICE guidance and National Service Framework (NSF) standards relating to children and young people with diabetes. It was distributed to the diabetes services in all 20 centres within the Yorkshire and Humber NHS Region. The response rate for this survey was 100 per cent.

All the centres were aware that children and young people with Type 1 diabetes may develop anxiety

and/or depression, and all (100 per cent) or virtually all (95 per cent) of them agreed with the various key requirements stipulated in the relevant NICE guidance and NSF standards.

Many of the centres lack key services. For example:

- Children and young people with persistently poor glycaemic control should be screened for anxiety and depression. Only 20 per cent of centres provide this screening. Of the 80 per cent that do not, 25 per cent are taking steps to provide this.
- Children and young people with Type 1 diabetes using multiple daily injection regimes should be offered structured behavioural intervention strategies to improve psychological wellbeing and glycaemic control. Only 5 per cent of centres have implemented such strategies. Of the 95 per cent that have not, 30 per cent are taking steps to provide this.
- Young people with Type 1 diabetes should be offered specific support strategies, such as mentoring and self-monitoring of blood glucose levels supported by problem solving, to improve their self-esteem and glycaemic control. Two fifths (40 per cent) of centres do not provide this, although 10 per cent are taking steps to do so.

The findings of this study are of national significance given the nature and size of the region studied. There is a general awareness within diabetes services and teams of the need for psychological support and care for young people with diabetes in the transition period. Despite this, multiple gaps exist in the services specified by existing requirements and standards. The survey authors suggest that commissioners:

- should expect and require services to rapidly work towards being able to demonstrate compliance with existing guidance and standards relevant to the psychological care of people with diabetes in the transition period; and
- should resource those services adequately to enable the necessary service development to take place.

The authors explain that the situation across the UK as a whole is highly unlikely to be different from the large region examined in this survey.

⁹³ Diabetes UK (2006)

⁹⁴ Harris et al (2007)

⁹⁵ Trigwell, P. and Jawad, S. (2010)

Case Study 5: Leeds Community

Psychological support service in the Leeds Community Diabetes Team

Background

A four-tier diabetes service model commissioned by Leeds Primary Care Trust incorporates an emotional and psychological support function. This is delivered by a full time clinical psychologist on secondment from the local acute trust and two half-time mental health practitioners employed by the Primary Care Trust. They provide the psychological support service of an integrated community diabetes team for Leeds.

The psychology team members have a range of experience and skills and between them have experience of delivering mental health services in community and acute settings, and providing psychological support to people with physical health conditions. The service is jointly managed by the Primary Care Trust and acute trust and was developed as a pragmatic response to identified need.

Services provided

The service aims to provide:

- Expert psychological assessment of complex psychological needs and risk.
- Direct clinical support for a range of conditions including eating disorders, needle phobias, anxiety, depression, adjustment and concordance issues.
- Training, consultancy, support and supervision for community diabetes team members.

Characteristics underpinning success

- The development of the service was driven by the initial actions of commissioners who recognised the important role for this service, as part of the overall service.
- The need for training, consultancy and support for the wider diabetes team was stipulated as an equally important role for the psychology service, as well as the provision of direct psychological support. Training encompasses a range of relevant areas including communication skills, assessment and management of anxiety and depression and the use of cognitive behavioural therapy with people with long term conditions. Eight successful training days have already been held including days on motivational interviewing and eating disorders (in partnership with the Yorkshire Eating Disorders Unit). This approach helps embed psychological support within diabetes care delivery, although more complex cases can always be referred on.
- Excellent working relationships have been established with other members of the diabetes team and they have worked together to develop referral criteria and forms, information leaflets, screening tools and assessment protocols.

A frustration to date has been the lack of opportunities to deliver joint clinics with other members of the diabetes team. A one year evaluation of the psychology service is being undertaken, looking at client-completed outcome measures and the views of the community diabetes team members.

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The fourth national survey of paediatric diabetes services in the UK

Deficiencies in the provision of psychological support for children, young people and their families were shown in the results of the survey. A questionnaire was mailed to all paediatricians in the UK identified as providing care for children and adolescents with diabetes. Responses were compared with results of three previous surveys, and with recommendations in the Diabetes National Service Framework and the NICE Type 1 diabetes guidelines. Replies were received from 187 consultant paediatricians in 169 centres providing care for children and adolescents with diabetes.

The survey shows continuing improvements in organisational structure of services for children with diabetes but serious deficiencies remain, with 78 per cent of these clinics reporting no access to psychology/psychiatry services.⁹⁶

Inequalities in service provision

Inequalities exist in access to healthcare and provision of emotional and psychological services, with some individuals and communities poorly served and seldom heard. Barriers to accessing services include experience of discrimination, inappropriate service delivery, inaccessible health information, low expectations (preventing or delaying access to healthcare), and a lack of cultural understanding among service providers.⁹⁷ For example, people from Black, Asian and minority ethnic communities are more likely to be compulsorily detained or admitted to hospital rather than treated in the community, with regard to their mental health needs.⁹⁸

The Disability Rights Commission's investigation⁹⁹ into the physical health inequalities experienced by people with mental health problems and learning disabilities reveals that people from these high risk groups are less likely to receive expected physical health checks and treatments. For example only 68 per cent of people with schizophrenia and heart disease, a long term complication for diabetes, had cholesterol tests compared to 80 per cent of people without schizophrenia. Furthermore only 66 per cent of people with schizophrenia and coronary heart disease (CHD) were likely to be prescribed statins compared to 81 per cent of people with CHD but not schizophrenia.

The report points to 'diagnostic overshadowing' whereby physical health issues are attributed to the mental health condition or learning disability and are not treated as they should be. This is seen as a significant barrier to enabling people to access the healthcare they need. It also impacts negatively on trust and the relationship between an individual and their healthcare professional. Inequalities in access to healthcare were also found to be exacerbated in older people and people from Black, Asian and minority ethnic communities with mental health conditions.

It is vital that all people with diabetes, including children, young people and those from communities whose voices are seldom heard, are involved in the process of local service design to ensure that service provision is not only needs-led but also tackles current barriers to service access. For a fuller discussion of health inequalities, see Appendix D.

⁹⁶ Arch Dis Child. (2005)

⁹⁷ All Parliamentary Group for Diabetes and Diabetes UK (2006)

⁹⁸ Department of Health (2005b)

⁹⁹ Disability Rights Commission (2006)

5. The evidence base for intervention

The evidence presented in this section is a summary of a specially commissioned review for inclusion within this document, undertaken by Dr Jackie Sturt and Kathryn Dennick at Warwick Medical School.

The review examined systematic reviews, recently published studies and relevant examples of best practice.¹⁰⁰ Reviews were included if they investigated interventions with an emotional or psychological component, or psychosocial interventions with psychological outcomes, with any diabetes population with a specified psychological need.

From an initial search revealing 2067 references, a total of 46 unique individual studies of both Randomised Control Trial (RCT)/non RCT study design and in-service examples, and two within-review summaries of a review, published or submitted between 1982 and 2008 were included.

The pyramid model

The evidence is mapped on to the five levels of the pyramid model described in Section 2. Reviewing the mapping of the evidence relating to interventions at all levels found that evidence is mostly focussed on the lower levels of the pyramid model. The descriptions which are contained within this section are by no means a definitive list of interventions or fully representative of the needs of a specific population.

Level 1

Interventions at level 1 address the commonly experienced difficulties of coping with diabetes. These include difficulties experienced by people coping with a new diagnosis, people beginning

intensive insulin regimens and young people transferring to adult services or experiencing family conflict related to diabetes and its management.

The interventions described at this level focus on education, self-management and peer support. All the following have one or more beneficial outcomes:

- Peer support¹⁰¹
- Group coping skills training including stress management¹⁰²
- Programmes that include emotional peer support: home-based and outpatient intensive follow-up,¹⁰³ group self-management training¹⁰⁴ and group education¹⁰⁵
- Group or individual diabetes education including cognitive therapy and either counselling and psychotherapy¹⁰⁶ or relaxation techniques¹⁰⁷
- Family therapy: Behavioural Systems Family Therapy including problem solving and communication skills therapy,¹⁰⁸ or multi-systemic family therapy in conjunction with Cognitive Behavioural Therapy (CBT) and peer support;¹⁰⁹
- Group or individual education (home or outpatient based)¹¹⁰
- Family self-management training¹¹¹
- A combination of group education and self-management training (usually community based)¹¹²

Only the interventions described in the first five bullet points have explicit emotional and psychological components; the remainder nonetheless have beneficial emotional and psychological outcomes.

¹⁰⁰ Ismail K et al (2004), Winkley K et al (2006)

¹⁰¹ NICE (2009), Lorig et al (2009)

¹⁰² Davidson et al (1997), Grey et al (1999; 2000), Grey et al (1998)

¹⁰³ Galatzer et al (1982)

¹⁰⁴ Thoolen et al (2008)

¹⁰⁵ North Cheshire Hospitals Warrington Hospitals (2007)

¹⁰⁶ Speiss et al (1995)

¹⁰⁷ Sturt et al (2008)

¹⁰⁸ Sundelin (1996), Wysocki et al (1997; 1999; 2000; 2001)

¹⁰⁹ Ellis et al (2007)

¹¹⁰ Dougherty (1998; 1999), Siminerio (1999), Scrivasan (2004), Rickheim (2002)

¹¹¹ Gross et al (1995)

¹¹² Davies et al (2008), Langewitz et al (1997)

Level 2

Interventions at level 2 address more severe difficulties with coping which may cause significant anxiety, distress, anger or low mood but do not cross the threshold for a diagnosable condition.

The following interventions and combinations of these interventions have been found to have beneficial outcomes depending upon severity:

- Cognitive behavioural stress management reduces psychological distress¹¹³
- CBT reduces diabetes-related distress and anxiety¹¹⁴
- Antidepressant therapy (Paroxetine) improves mood, quality of life and HbA1c¹¹⁵
- Blood glucose awareness training reduces worry about hypoglycaemia and feelings of hassle and distress in relation to diabetes, and improves quality of life.¹¹⁶

Level 3

Interventions at level 3 address states of psychological distress that are recognised as diagnosable conditions but which require psychological intervention rather than biological treatment. Conditions include milder and some moderate cases of depression (but not severe depression), anxiety and eating disorders.

The following interventions have been found to have beneficial outcomes:

- Group or individual psychotherapy leads to benefits in psychological problem severity,¹¹⁷ relationships with health care providers and significant others,¹¹⁸ and metabolic control¹¹⁹
- Group CBT with education reduces binge eating¹²⁰
- Integrated inpatient therapy involving behavioural

training and family therapy leads to benefits in eating disorder psychopathology, depression, anxiety, binge eating and purging behaviour, and HbA1c¹²¹

- Group blood glucose awareness training benefits depression¹²²
- Psycho-education including attention to diabetes-related body image concerns, disordered eating and insulin omission improves eating-disordered attitudes and food restriction¹²³

One particular randomised control trial study, the ADaPT study, concluded that nurse-delivered motivational enhancement therapy with CBT is feasible for adults with poorly controlled Type 1 diabetes. Combined therapy resulted in clinically significant 12-month improvement in HbA1c levels compared with usual care, but motivational enhancement therapy alone did not.¹²⁴

Up to 25 per cent of adolescents with diabetes fail to take insulin or measure blood glucose levels because they do not believe the treatment is necessary.¹²⁵ In children and young people a motivational and solution focussed approach was found to be acceptable to children and has produced beneficial outcomes.¹²⁶

Level 4

Interventions at level 4 address more severe psychological problems in comparison to Level 3, satisfying the criteria for diagnosis, typically requiring biological treatment and complex psychological intervention. These include anxiety disorder, severe depression and panic attacks relating to hypoglycaemia.

The following interventions have been found to have beneficial outcomes:

¹¹³ Henry et al (1997)

¹¹⁴ Hains et al (2001)

¹¹⁵ Paile-Hyvarinen et al (2003)

¹¹⁶ Weinger et al (2001)

¹¹⁷ Didjurgeit et al (2002)

¹¹⁸ Ginieri-Coccosis & Vaslamatzis (2008)

¹¹⁹ Huang et al (2001), Didjurgeit et al (2002)

¹²⁰ Kenardy et al (2002)

¹²¹ Takii et al (2003)

¹²² Cox et al (2001)

¹²³ Olmsted et al (2002)

¹²⁴ Ismail et al (2002)

¹²⁵ Weissberg-Benchell J et al (1995)

¹²⁶ Viner RM et al (2003)

- Antidepressant therapy may lead to improvements in depression¹²⁷ but this has not been consistently observed
- Individual and group CBT improves fear of hypoglycaemia and anxiety,¹²⁸ depression¹²⁹ and self-care behaviour;¹³⁰ and may improve glycaemic control¹³¹ but this has not been consistently observed¹³²
- Psychodynamic supportive psychotherapy improves diabetes-related distress, anxiety and depression;
- Collaborative, stepped-care depression programmes involving antidepressants and either problem-solving counselling or problem-solving psychotherapy lead to benefits in quality of life,¹³³ body mass index,¹³⁴ depression and reduced outpatient care costs;¹³⁵
- An integrated care psychiatric intervention involving supportive counselling, psychiatric referral and liaison with providers of medical care improved depression, general and health-related quality of life.¹³⁶

Level 5

There is a serious lack of randomised controlled trials for effective models of care that aim to reduce the risk of diabetes or to optimise diabetes control, or studies which combine diabetes care with improving the mental health of those people who

also have a severe and complex mental illness. However naturalistic studies suggest that interventions such as monitoring of metabolic factors and supervised exercise programmes could help reduce weight gain associated with anti-psychotic medication.¹³⁷ There is a significant gap in the knowledge base on what are the additional psychological needs of people with diabetes who also have severe, complex and enduring mental illness and how their mental health care can be optimised to take account of their diabetes.

Conclusion

Most current evidence relates to interventions at level 1, which focus on patient education and self-management. Although there are gaps in knowledge about effective interventions at higher levels, there is strong evidence underpinning the specific interventions described at levels 2 and 3. Little research has been undertaken to develop and evaluate interventions at levels 4 and 5. The diabetes and mental health community needs both to continue to gather the evidence, develop the innovative practice and to ensure that the needs of people with diabetes and severe mental illness are properly addressed.

¹²⁷ Cheer & Goa (2001), Lustman et al (1997), Lustman et al (2006)

¹²⁸ Boyle et al (2004)

¹²⁹ Boyle et al (2004), Lustman et al (1998), Georgiades et al (2007)

¹³⁰ Snoek et al (2008)

¹³¹ Boyle et al (2004), Lustman et al (1998), Snoek et al (2008)

¹³² Simson et al (2008)

¹³³ Katon et al (2006), Williams et al (2004)

¹³⁴ Lin et al (2006)

¹³⁵ Katon et al (2006), Williams et al (2004), Simon et al (2007)

¹³⁶ Steifel et al (2008)

¹³⁷ Poulin MJ et al (2007)

Case Study 6: Kings College London

The Diabetes & Mental Health Service at Kings College Hospital, King's Health Partners

Background

Since 2003, we have provided a comprehensive mental health service funded by and embedded into the Diabetes Centre which provides secondary and tertiary diabetes care to one of the most ethnically and socio-economically diverse populations in the UK. It was shortlisted for the Clinical Audits Award 2009. The components of our service are as follows:

Services provided

We accept referrals from any diabetes related health professional, GP, dietitian, diabetes specialist nurse, doctor as we want to ensure visibility and accessibility and recognise that diabetes professionals are good at detecting psychological problems. Each case is discussed by the psychiatrist and psychologist and triaged. We meet weekly to discuss new referrals and allocate them to the appropriate service.

The clinical psychologist as part of the diabetes multi disciplinary team contributes to discussion and planning future care of complex cases. The psychiatry clinic runs one day/week. It offers diagnostic assessment of psychiatric disorders and psychological problems and treatment (both psychotherapeutic and pharmacological).

The psychology clinic runs one half day/ week. It offers an assessment of psychological difficulties impacting on diabetes or vice versa. Interventions offered include: CBT, neuropsychological assessments, Motivational Enhancement Therapy for people with Type 2 diabetes. Patients can also access a Mindfulness Based Cognitive Therapy group.

Characteristics underpinning success

DSNs trained in Motivational Interviewing deliver this intervention for people with Type 1 diabetes with motivational issues. We can see inpatients on an ad hoc basis following a referral directly from the consultant.

We take on very complex, usually multi-morbidity cases as 'key workers' to facilitate multiple pathways of care such as social interventions (housing, immigration, financial), further diagnostics and assessment and liaison between different health providers e.g. community and hospital.

We can also refer patients on for other therapy options including Interpersonal Therapy and Cognitive Analytical Therapy, as well as other mental health services (e.g. Eating Disorders Unit) as part of the King's Health Partners where we work closely with the South London and Maudsley Mental Health Trust and Guy's and St Thomas's Hospitals.

We run a popular and interactive 'Diabetes and Mental Health' journal club on the first Thursday of every month to present latest research activity, increase awareness and knowledge of psychological problems and encourage reflective practice.

We are also involved in two Masters modules/courses for health professionals led by Dr Angus Forbes (angus.forbes@kcl.ac.uk):

- Skills in psychological assessments in diabetes
- Motivational Interviewing for chronic health conditions

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6. Commissioning

Introduction

Evidence suggests that providing emotional and psychological support as part of diabetes services can lead to long term saving from complications and delayed need for specialist services.

Commissioners need to consider four key questions when commissioning emotional and psychological care within diabetes services:

1. Where are we now?

Commissioners need to commission services based on a thorough assessment of local needs and existing service performance reviews.

2. Where do we want to be?

The pyramid model presented in Sections 2 and 5 provides a framework for considering the range of emotional and psychological care interventions required to meet the needs of people with diabetes and identifies a range of skills and competences that will be required to deliver this support at a local level. This care is underpinned by the quality markers that all services need to strive towards, such as National Service Framework standards, the guidance of the NICE and national targets.

The documents described in Section 3 provide a wealth of insight into the character, severity and prevalence of emotional and psychological need. In particular, this question should be informed by the guidance set out in the IAPT programme, the document Making Every Young Person with Diabetes Matter and the latest developments in the area of severe mental health such as the New Horizons document from the Department of Health.

3. How do we get there?

Neither the Pyramid Model nor this document can offer a comprehensive account of needs in any local area. Decisions about local priorities and the specification of interventions to meet the specific needs of the local population are a matter for local determination, though template service specifications are available in the NHS Diabetes Commissioning Guide.

Examples of service models in different parts of England are presented throughout this document. Section 7 on workforce planning and competences also provides a useful guide to emotional and psychological support for people undertaking service redesign.

4. How will we know when we are there?

The National Service Framework and other national guidelines should be used to assess whether commissioned services are appropriate to meet the needs of the whole community.

The NHS Diabetes Commissioning Guide demonstrates how automated healthcare needs assessment (generated by the National Diabetes Information Service)¹³⁸ can assist the commissioner to commission for demonstrable outcomes including patient satisfaction.

Health and healthcare needs assessment

The diabetes commissioning guide includes advice on an approach to carrying out a healthcare needs assessment for a whole local diabetes population which will provide a comprehensive picture of the level of demand for diabetes services in a locality.

Commissioners and providers should involve other stakeholders in assessing needs. Public health and information specialists can help to identify data sources over and above those provided by the National Diabetes Information Service, while other staff such as youth workers may be able to collect service user, staff and other stakeholder views. User involvement tools have been developed for both adults and children with diabetes.¹³⁹

There are many components to needs assessment, and commissioners and others involved in developing emotional and psychological services within diabetes should consider the following:

¹³⁸ <http://ndis.ic.nhs.uk>

¹³⁹ See National Diabetes Support Team (2007) for a guide to user involvement in diabetes care planning; see National Diabetes Support team (2008) for a guide to involving children and young people in diabetes services

Population profiling

The magnitude of diabetes and emotional and psychological need can be assessed using data on:

- prevalence and incidence (including local, regional and national trends)
- assessment of the emotional and psychological needs of different populations living with diabetes
- type of diabetes
- age profile, age at diagnosis
- local health burden: hospitalisations, length of stay, complication rates
- health inequalities: ethnicity, care of older people, veterans, children, deprivation, learning disabilities and poor basic skills, co-morbidities, and seldom heard groups such as travellers, asylum seekers, prisoners, refugees and children in care
- risk factors: those not yet diagnosed with diabetes but at risk (this is necessary to inform forward planning, particularly in groups with relatively small numbers of new cases which may represent a significantly increased demand for emotional and psychological services)
- expenditure with consideration of wider costs such as social services; and comparative level of risk and need

Profiling can be undertaken as a discrete piece of work but the final profile should be agreed and validated by a diabetes network/forum or wider stakeholder group to ensure that local perspectives and issues are taken into account.

Effectiveness and cost-effectiveness of current diabetes services in meeting emotional and psychological needs

A randomized controlled trial, the ADaPT study concluded that nurse-delivered motivational enhancement therapy with cognitive behavior therapy is feasible for adults with poorly controlled Type 1 diabetes. Combined therapy resulted in clinically significant twelve month improvement in HbA1c levels compared with usual care, but motivational enhancement therapy alone did not.¹⁴⁰

In 1993 a Diabetes Control and Complications Trial demonstrated that any decrease in glucose levels

was associated with a decrease in the development of microvascular complications.¹⁴¹

With appropriate skills training, diabetes nurses can deliver behaviour change strategies that improve glycaemic control.

The focus on patient-identified problems rather than on general psychological distress may inform translating these findings into practice current services should identify:

- current emotional and psychological need and demand
- current provision of emotional and psychological support, uptake and workforce capacity
- projected trends
- cost-effectiveness, local implementation of known effective measures
- user satisfaction and perceptions of emotional and psychological needs, this should include current service users, parents and other carers as well as those not currently using services and those in contact with specialist mental health services
- staff and other stakeholders' views of emotional and psychological support
- processes, attendance at clinics, opportunities to educate service users and their families about diabetes and supporting education, access to specialist staff, screening uptake, access to stop smoking and sexual health services, transition arrangements
- glycaemic control, hospital admissions, complication rates, quality of life, ambulance call outs, excess bed days

Developing a commissionable service specification

Commissioners have a duty to ensure that services which support the emotional and psychological needs of people with diabetes are available and appropriate for everyone in the local community, including individuals from seldom heard groups. This requires that commissioners involve local people with diabetes in the process of identifying needs and designing suitable services. User involvement is a fundamental requirement for all

¹⁴⁰ Ismail K et al (2008)

¹⁴¹ The Diabetes Control and Complications Trial Research Group (1993)

service design and delivery in the NHS and is an important component of local accountability. Health and social care Local Involvement Networks (LiNs) and Patient and Public Involvement teams are key to ensuring that appropriate representation and engagement occurs.

Specifying a service is a key part of the service design stage within the commissioning cycle. It requires that commissioners match national quality guidance to local population needs and arrive at locally appropriate service specifications addressing all the elements of a comprehensive diabetes service. The Diabetes Commissioning Guide offers a variety of resources to enable this process. These commissioning care guides include patient intervention maps or high level service pathways; contracting frameworks, which set out the minimum standards within which diabetes services should operate; and template service specifications that link to the Standard NHS Contracts.

Commissioners have to balance many things in determining the range of services for their local community. The Guide specification aims to support commissioners in making judgements about emotional and psychological support within diabetes services. Using this specification will provide assurance to commissioners, staff and people with diabetes that key success factors for services have been taken into account.

Outcomes that services should as a minimum include:

- improvements in the psychological wellbeing of the person with diabetes, demonstrated by pre- and post-assessment questionnaires, such as HAD scores and PROMS
- increased patient empowerment, leading to increased ability to self-manage and improved physical health, measured by the Diabetes Empowerment Scale (DES) or PROMS and assessed by patient experience questionnaires, interviews and by monitoring of the achievement of goals as set by the individual with diabetes in the care planning process

- improved access to services
- enhanced health and social wellbeing

A focus on outcomes helps to:

- facilitate the development of integrated care pathways
- improve communication between professionals, and between people with diabetes and professionals
- improve quality and productivity
- underpin robust contractual arrangements

Costs

The prevalence of depression in people with diabetes is two to three times the rate of the general population¹⁴² and diabetes combined with depression is strongly associated with increased mortality.¹⁴³

Diabetes costs are increased by the presence of co-morbid depression. An American estimate put the costs of co-morbid depression to be 251 per cent in excess of standard diabetic care, and 400 per cent greater for all types of care.¹⁴⁴ The cost of diabetes care in the UK is estimated to be £1.3billion, or 9 per cent of all hospital costs.¹⁴⁵

Systematic care of depression in diabetes has been shown to significantly increase time free of depression and lead to lower outpatient service costs than usual care¹⁴⁶. Using data on the prevalence of diabetes and co-morbid depression (available through the Quality Outcomes Framework), Primary Care Trusts can calculate the potential savings of better management of people with depression and diabetes. The IAPT website¹⁴⁷ contains further reading, business case templates and an economic benefit calculator.

Generic issues

Diabetes services that aim to provide appropriate emotional and psychological services should:

- be timely, accessible and equitable;
- be developed in a co-ordinated way as part of diabetes and mental health plans, such that

¹⁴² Nichols (2007)

¹⁴³ Ismail et al (2007)

¹⁴⁴ Trong (2006)

¹⁴⁵ Wanless (2002)

¹⁴⁶ Katon (2007)

¹⁴⁷ www.iapt.nhs.uk

comprehensive, integrated care is delivered in collaboration with mental health trusts and other partners, including the private and third sectors;

- recognise and fulfil the duty to co-operate in order to promote the wellbeing of people with an emotional and psychological support need and make arrangements to safeguard and promote the welfare of vulnerable groups;
- be designed in response to the local needs assessment, to meet the specific needs of the local population, including groups who are seldom heard and individuals with more complex needs such as other medical conditions;
- be designed through an inclusive process that involves people with diabetes and clinicians with both specialist and generalist expertise;
- meet the data quality criteria and information governance criteria to cover confidentiality consent;
- offer a range of options and information to support self-management, informed choice and individual preferences;
- value and address emotional and psychological needs in all care settings including home, community and hospital;
- be available to people who are excluded from some or all local health services, such as children in care, children in the secure estate, refugees and asylum seekers;
- have specific local agreements that enable 24-hour access to emergency advice from competent staff;
- consider provision of care as well as emergency advice outside the core hours of 9am to 5pm, Monday to Friday;
- ensure the transition of care from provider to provider is negotiated and planned around the assessed needs of each individual, using an explicit care planning approach;
- ensure and demonstrate that staff have the competences needed to deliver the functions necessary to meet the full range of emotional and psychological need (see next section);
- be covered by written protocols and guidance that are adhered to and monitored;
- have agreed local standards for key outcomes such as timeliness, continuity of care, monitoring for complications;
- contribute to national data collections or audits;
- be quality assured and have arrangements in place for local audit, benchmarking against national standards (including patient experience);
- actively monitor take-up, respond to non-attendees, monitor complaints and manage outcomes across the population of service users by seeking out areas and individuals where further input would create improvements.
- actively monitor take-up, respond to non-attendees, monitor complaints and manage outcomes across the population of service users by seeking out areas and individuals where further input could reduce inequalities and improve equity of service.

Case Study 7: Bournemouth

Bournemouth Diabetes Psychological Service

Background

Diabetes UK funded a research project at the Royal Bournemouth Hospital to assess the prevalence of psychological morbidity in the Type 1 diabetes outpatient clinic and to compare interventions delivered by a clinical psychologist and a diabetes specialist nurse. Significant levels of psychological distress were identified in more than half of participants and a clinically relevant reduction of HbA1c was obtained from both interventions. A third group of patients self-selected to receive the psychological intervention and were found to have more complex presentations, greater psychological distress and higher HbA1c. This group demonstrated the greatest improvements in all variables assessed and all intervention groups maintained improvements over two years of follow up. As a result, funding was secured in 2005 to establish a psychology post within the diabetes team. In the Bournemouth locality people with Type 1 diabetes usually receive their care from the hospital outpatient department. While the clinical psychology service is available to all patients attending the Diabetes Centre, the greatest proportion of people seen have Type 1 diabetes.

Services provided

The secondary care team includes consultants and specialist registrars, diabetes specialist nurses, dietitians, podiatrists and a consultant clinical psychologist.

The clinical psychologist is an integral member of the diabetes team which serves a population of about 200,000. Psychological care is embedded in all aspects of the diabetes service, diabetes knowledge having been learned primarily from people with diabetes and colleagues together with participation in the local education programmes for Type 1 and Type 2 diabetes.

The psychologist works with the diabetes team and psychological care is embedded in all aspects of the diabetes service. The diabetes team at the Royal Bournemouth Hospital serves a population of about 200,000.

The role of the clinical psychologist includes

- 1:1 therapy – multiple presentations, including self-referral
- Input into the multidisciplinary group clinic for newly diagnosed Type 1 adults
- Input into structured education programme for Type 1 diabetes
- Supervision of team members
- Consultative role
- Training and education for multidisciplinary team when required
- Audit of psychological outcomes
- Research
- Psychological intervention for weight management

Self-report questionnaires are used in a variety of contexts including

- Screening in the outpatient clinic
- Pre and post measures for structured education, newly diagnosed group
- 1:1 therapy outcomes

Factors underpinning success

Patient feedback about the service is very positive and people with diabetes from other areas frequently express surprise at the existence of this aspect of the diabetes service. People who complete the intervention typically demonstrate a clinically significant reduction in HbA1c together with an average reduction in diabetes specific distress greater than 50 per cent.

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7. Workforce development and planning

A diverse range of skills are required to meet the full range of emotional and psychological needs of people living with diabetes. Just as different interventions (Section 5) are required to address different needs (Section 2), so too are different skills and competences required to ensure that all interventions are delivered to a high standard.

The following workforce-related recommendations from Diabetes UK's assessment of psychological support services for people with diabetes in the UK¹⁴⁸ define the overall objectives of workforce development and planning in this area:

- People with diabetes in the UK should not have to rely for their psychological help and treatment upon the best efforts of people who are not adequately trained or supported, to carry out that work. Diabetes healthcare professionals should be trained and supported to enable them to deliver emotional and psychological support themselves, at an appropriate level, with the aim of embedding this as an integral part of healthcare professional training for the future.
- Specialist psychological services need to be able to provide direct clinical care with appropriate psychological therapies and biological treatments (medication) where necessary, as well as clinical supervision, education and training for members of the diabetes multidisciplinary team.
- Expert psychological care for people with diabetes needs to be provided by professionals with specific knowledge and experience in the area of diabetes. This is in order that psychological assessment and treatment will be provided in the context, and with an adequate understanding, of the particular issues faced by people with diabetes.

Commissioners and service providers each have their role to play in ensuring that all professionals working with people with diabetes are competent to deliver services to the level required.

The role of commissioners in the workforce planning process

Commissioners will need to ensure that the right people will be in the right place at the right time to meet the needs of people with diabetes in their local population, including their emotional and psychological needs. The responsibility for the development and provision of workforce plans lies with providers but service commissioners will need to strategically understand those plans and how they have been developed. Commissioners will need to ensure that their service provider(s) have workforce plans that take account of demographics and the local health and equality and diversity needs of the community they serve.

It is important that commissioners have an understanding of these issues to enable them to effectively assure themselves that any provider(s) they commission services from have the right number of people, with the right skills, to deliver high quality services that improve care for people with diabetes and that they have in place training plans to ensure this will be sustainable.

However assurance does not stop after a workforce plan has been presented. There must be a process for reviewing the progress of a provider(s) workforce plan, including whether it has been implemented and reviewed. As part of the contract commissioners should at the very least be expecting a regular report from their provider(s) on progress made against the workforce plan. The effect of not challenging or questioning providers may mean that gaps will not be identified which may lead to unsustainable services or other difficulties which impact on the quality of service delivery.

Service providers

Service providers will need to ensure that they have in place a workforce plan which recognises that providing psychological support to people with diabetes requires skills appropriate to each of the five levels of need identified in the pyramid model.

¹⁴⁸ Trigwell et al (2008)

Specialist services helping people with psychological problems are not the exclusive domain of any single discipline or profession. Several types of healthcare and mental health professionals may be involved in providing psychological services for people with diabetes such as counsellors, psychologists, liaison psychiatrists and psychotherapists. As such professionals tend to provide a range of different interventions and treatments, it is crucial to match skills to need.

Health care professionals working with children and adolescents should have specialist training in, and knowledge of, child development and adolescent health with additional specific competences at all of the levels within the pyramid model. Educating children, young people and their families about diabetes can be more challenging due to the age and stage of development. Diabetes educators must be competent therefore in educational theory, child development theory and practice as well as having sufficient diabetes knowledge.

The minimum knowledge and skills required to deliver an integrated service vary greatly at each level of the pyramid model for emotional and psychological support as they do for overall diabetes services. Competences for each level are local service specific and Appendix C contains links to current sources of competences and standards. This is not intended to be an exhaustive list of all the knowledge and skills required but instead should be used by service providers as a starting point for workforce design, development and planning.

Below is a non-exhaustive list of some of the skills and knowledge requirements, which it is felt, are most relevant and useful in the real day to day world operating at each level. The levels are **cumulative**, i.e. each level assumes that the skills and knowledge described in lower levels are in place.

Level 1 –

Foundation skills:

- Basic knowledge of diabetes
- Good communication skills including expressing

empathy, establishing rapport and reflective listening

- Basic techniques for supporting people with diabetes through goal related discussions
- An awareness of common mental health problems relevant to diabetes
- Signposting to further assessment if necessary
- Skills in the early identification of depression, using the two recommended initial screening questions for adults and more appropriate tool for children and young people:
 - *During the last month, have you often been bothered by feeling down, depressed or hopeless?*
 - *During the last month, have you often been bothered by having little interest or pleasure in doing things?*

Level 2 –

Basic intervention skills:

- Extended communication skills including some counselling skills (with supervision) such as ability to provide alternative perspectives
- Effective information giving skills
- Basic problem formulation and solution focused therapeutic skills
- Delivery of psychological interventions at a low intensity and to an appropriate level of competency
- Experience of delivering low intensity interventions which lend themselves to diabetes services, (e.g. Structured Education, dietary education, exercise changes, group support), and other recommended first line depression (mild-moderate) treatments.

Level 3 –

Psychological intervention skills:

- Competent at assessment for psychological distress using established measures and ability to identify key features of common psychopathology
- Consultancy skills (training multidisciplinary teams/carers/families)

¹⁴⁸ Trigwell et al (2008)

- Research evaluation and audit skills
- Advanced Counselling and/ or established competences and skills at delivering intermediate psychological intervention including specific psychological approaches e.g. Motivational Interviewing (MI), CBT/Solution Focused Therapy skills, (SFT). (CBT skills would include 'Ability to challenge dysfunctional health beliefs therapeutically')

Level 4 –

Psychiatric and advanced psychological intervention skills:

- Assessment, case formulation, treatment, research, audit, teaching and supervision
- Psychiatric diagnosis and prescribing
- Ability to select and deliver a range of treatment interventions.

Level 5 –

Advanced specialist psychiatric and mental health skills:

- Case management skills (collaborative care planning for severe and complex cases)
- Ability to select and deliver a range of intervention types to a range of mental health issues
- Dedicated mental health teams in both community and acute settings, have adequate knowledge of diabetes.

Service providers will also need to have in place a training and development plan including access to continuing professional development and mechanisms for assessing competence.

Human Resources policy and practice should include mechanisms for appraisal and access to continuing professional development.¹⁴⁹

Taking a competence based approach

Skills for Health is the Sector Skills Council for the health sector. The organisation aims to help the whole UK health sector develop a skilled, flexible and productive workforce to improve the quality of healthcare.

Skills for Health promote a competence-based approach to workforce design. Rather than beginning with professional roles, this approach focuses on the functions, skills and knowledge required to deliver a service to meet a given need. The following is a summary of the key steps in competence-based workforce design. Skills for Health offer a range of tools to assist in this process:¹⁵⁰

- Be clear about the service need and understand the financial and workforce implications that entails.
- Take a fresh look at the functions your service provides and the competences those delivering the service will need.
- Develop a plan to make best use of existing and potential talent within the workforce.
- Recognise the importance of change management and ensure the resources and accountabilities are in place to secure your goals.
- Understand the forces affecting change – consider the implications of national and regional policies and other drivers that may affect your plans.
- Think about sustainability and your capacity for workforce planning for the future. The 'Six Step Model'.
- Ensure you can develop the workforce you need for the future with an effective Workforce Strategy.

Taking a competence based approach enables the identification of skills gaps, the design of education and training, and the development of job descriptions and role profiles. National Workforce Competences and National Occupational Standards can be used to embed psychological support in all care pathways and for clarifying the boundaries of every professional's role.

Appendix C provides information on a range of workforce resources to support workforce design, development and planning.

149 see www.nhsemployers.org.uk

150 <http://www.skillsforhealth.org.uk/workforce-design-development/workforce-design-and-planning/competence-based-workforce-design.aspx>

Case Study 8: South Staffordshire and Shropshire

South Staffordshire & Shropshire NHS Foundation Trust, CAMHS Paediatric Psychology Specialty

Background

Ten years ago, referrals of children with chronic illness had to wait almost two years to be seen as they joined an already saturated CAMHS waiting list. Locality audits revealed that there were 350 children and young people with diabetes spread between two district general hospitals in the area.

Children and young people with diabetes and their families were unable to access specialist psychological services. These services have been shown to make a demonstrable difference to their mental health and psychological well-being, as well as their physical health, treatment adherence and coping capacity.¹

Services provided

A paediatric psychology service, integrated within the paediatric department at one of the general hospitals, was developed in partnership. The core team consists of a Consultant Paediatric Clinical Psychologist (children and families) and a Paediatric Psychology Specialist Nurse (adolescents and transition) who provide psychological interventions and support to children and young people with diabetes and their families through being an integrated part of the diabetes team. Four sessions per month are delivered. Knowledge of diabetes has been gained through clinical practice, working with the multidisciplinary diabetes team, attendance at relevant workshops and through undertaking audit and research activities.

Factors underpinning success

The service is an excellent example of working creatively and 'smarter' with minimal resources:

- A fast track referrals system allows patients to be seen during their admission at the hospital when newly diagnosed and in the first three weeks at the outpatient insulin-dependent diabetes clinic.
- The integration of the paediatric psychology team within the medical paediatric diabetes team diminishes the stigma of being referred to mental health services.
- Ongoing consultation, case discussion and supervision help to develop the psychological skills of other paediatric staff.
- The creation of a specific multilevel care pathway with different stages of psychological intervention² makes the best use of resources.
- The creation of 'filters' for referrals to the paediatric psychology team, operated by other professionals. This helps to further develop psychological skills. An example is the health education groups run by the diabetes specialist nurse and hospital play specialists.³
- Rigorous application of key policies and NICE guidance.⁴
- Training of specialist nurses and hospital play specialists in psychological approaches (university accredited training within child psychology services) extends the skills and knowledge base.
- Ongoing training for doctors in psychosocial aspects of paediatrics through their teaching sessions.

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¹ Martin et al (2009a)

² Martin et al (2008)

³ Martin et al (2009b)

⁴ Martin, C., Marr, A., Whitehead, K., Randell, T & Milestones, J. (2008)

8. Conclusion and next steps

This report highlights the need for, and current lack of, emotional and psychological support for people with diabetes in the UK. Successful interventions exist, and are valued by those individuals able to access them, but good practice is far from commonplace. If emotional and psychological support for people with diabetes is to improve, the knowledge and skills of the healthcare professionals delivering diabetes care must improve first.

The recommendations presented here are consistent with the recommendations in the *Minding the Gap* report.

We recommend the following steps:

Commissioning

- The provision of psychological services for people with diabetes needs to be addressed in line with the clinical provision of services for diabetes for all age ranges. The emotional wellbeing of people with diabetes and improved access to psychological and psychiatric assessment and interventions needs to be prioritised within all current and future diabetes service improvements and developments.
- Commissioned services need to be matched to the assessed needs of people with diabetes locally, including those with SMI within the process of identifying needs, involving people with diabetes and their carers if appropriate. The use of local knowledge, expertise from across the spectrum of the overall local diabetes population and community should be also maximized.
- Commissioners should require services to demonstrate that they are able to provide effective identification, assessment and treatment of the psychological problems and disorders experienced by their diabetes population. Providers commissioned to deliver services should also demonstrate that the clinical supervision and continued professional development of all staff engaged in the management of diabetes and care delivery at all levels of the pyramid model, is undertaken.
- Specialist psychological services for people with diabetes should be provided across the full age range, with care being taken to ensure the

inclusion of appropriate psychological services at transition from children's to adults' services and from adults' services to older people's services.

- Commissioners should require services to rapidly work towards, and to demonstrate, compliance with existing NSF standards, NICE guidelines, national programmes such as IAPT, relevant to the psychological care of people with diabetes.

Work force

- The skills of the workforce need to be matched to the assessed needs of people with diabetes locally.
- Specialist psychological services need to be able to provide direct clinical care with appropriate psychological therapies and biological treatments (medication) where necessary, as appropriate within the pyramid model and in agreement with the person with diabetes.
- Expert psychological care for people with diabetes needs to be provided by professionals with specific knowledge and experience in the area of diabetes. This is in order that psychological assessment and treatment will be provided in the context of, and with an adequate understanding of, the particular issues faced by people with diabetes.
- The multidisciplinary diabetes team should be supported to help identify and provide care for the emotional and psychological needs of people with diabetes to an appropriate level. Specialist psychological services will need to provide the team with training and clinical supervision to improve their skills and competences.

Service delivery

- Psychological services should be designed to meet the range of needs identified in the Pyramid Model, including needs identified at Levels 1 and 2. As these needs have a very real impact upon self-management in diabetes, it is essential that they are seen as appropriate for assessment and treatment. Support at levels 1 and 2 may include support from families, peers and friends. The care planning process should involve exploration of an individual's emotional and psychological needs and how they can be met.
- All service developments should be needs-led, and the psychological needs of people with diabetes

should be addressed in an organised, planned and evidence-based way.

- The provision of any psychological service for people with diabetes should be determined by a balanced approach to the requirements placed upon the service to deliver direct clinical care, clinical supervision, education and training of the diabetes Multidisciplinary team and other providers of diabetes care.
- Current psychological service provision may need to be improved in line with the pyramid model, in all settings where people with diabetes may receive their care.
- Clinical services provided will need to involve a mix of routine and urgent care, the latter being genuinely responsive psychological (including psychiatric) care and be able to seamlessly move people with diabetes up and down the pyramid model.
- Guidelines, clinical care pathways, and protocols for the management and referral of common psychological conditions in diabetes should be developed and adhered to by all service providers, at each level of the pyramid. These should also be made available to people with diabetes and carers.

Cultural shift

- This document can be used as a guide for commissioners, clinical teams, people with diabetes and third sector organisations, to review the current level of local provision against an evidence-based model. Used in conjunction with the commissioning guides from NHS Diabetes, it can assist in the planning and implementation of local services improvement. Emotional and psychological care must be seen as part of the remit of the whole multidisciplinary team regardless of the care setting.

Next steps for emotional and psychological care in diabetes

- Use the evidence and guidance to influence the provision of resources available at the local and national level to ensure delivery of appropriate services at all levels of the model.
- To influence and inform the development of NICE Guidance, the Quality and Outcomes Framework and questions within DiabetesE. Encourage utilisation of existing questions within DiabetesE and the Care Quality Commission.
- Continue to review the evidence in terms of intervention, quantitative summaries of evidence to

define a way forward for further research and evaluation of model implementation.

- Developing psychological services for diabetes should consider how to develop or adopt appropriate screening tools to improve the recognition of psychological and emotional problems in people with diabetes within the local population.
- Metrics to assist in the audit and quality assurance of emotional and psychological services for people with diabetes need to be developed; this has started within the NHS Diabetes Commissioning Guide. An example of practical quality assurance could be a regional peer review of service provision.
- The provision of education in emotional and psychological care should form an integral part of all healthcare professional training in the future linking specifically with care planning as a means to further develop an empowering approach to consultations.

Research

- Most of what we know about the prevalence and incidence of emotional and psychological needs among people with diabetes has been identified in secondary care settings. Research is needed into the extent of need in primary care populations.
- Minding the Gap (which describes need and provision in secondary care) should be repeated in primary care where the majority of care for Type 2 diabetes takes place.
- A better understanding is needed of the efficacy of non-psychological specialists in delivering emotional and psychological care particularly at levels 1 and 2, and of their training and clinical supervision needs.
- Further development and evaluation is needed of interventions designed to meet the emotional and psychological needs of people with diabetes at levels 3, 4 and 5 of the pyramid model.
- Current work to design and evaluate care pathways at levels 4 and 5 should be expanded, through appropriate pilot sites, to include care pathways for levels 1 to 3.
- Cost-effectiveness data is all but absent and a programme of work needs to be commenced to understand the broad economic consequences of both ignoring and meeting the psychological needs of the growing population of people with diabetes.

Case Study 9: Brighton

Brighton Diabetes Service

Background

A project investigating the efficacy of cognitive analytic therapy (CAT) and intensive diabetes specialist nurse education in a randomised trial was conducted. On the basis of what occurred during the trial a full-time diabetes psychotherapy service was set up on both sites and the original model for this service has been running one day per week for five years in the diabetes centre at the Royal Sussex County Hospital, Brighton.

Service Provided

Psychotherapy referral process People are referred to the diabetes psychotherapist from other members of diabetes teams that are part of Brighton and Sussex University NHS Trust. The diabetes department has recently applied to the PCT for funding to increase the post to full time in recognition of the level of existing need. In the meantime, many patients are referred to the community IAPT service although this is not a condition specific service.

Service provided The psychotherapist works directly with the diabetes team and there is a monthly psychotherapy meeting where all team members attend and discuss potential referrals. The psychotherapist accepts appropriate referrals based on the criteria outlined above. Individuals are offered a full psychotherapy assessment and at the end of that session, if patients agree (95% do), they are placed on the waiting list to start psychotherapy. Most people receive between 16 and 20 sessions of Cognitive Analytic Therapy (CAT), which uses psychoanalytic techniques to bring about a change in thoughts and feelings. HbA1c and psychological wellbeing is measured before and after psychotherapy and continues to be monitored at annual review. Significant reduction in admissions and the use of diabetes education staff after psychotherapy is also recorded and reported. Although the psychotherapist is knowledgeable about diabetes, no diabetes education occurs during the psychotherapy.

The psychotherapist is also responsible for teaching/lecturing and training of medical students, joint supervision of medical student projects, and supervision of psychotherapy students on specialist (diabetes) placements and provides a consultative role to all members of the team, and mental health staff seeing patients outside of the diabetes unit. The current post holder provides clinical supervision to psychotherapists and clinical psychologists working in diabetes centres across the country.

Factors underpinning success Staff report that without a psychotherapy service they were seeing many people without being able to help them. Treatment is successful in terms of continued reduction in HbA1c levels and direct patient feedback has been extremely positive.

Service development Research has shown that over a third of patients in the diabetes clinic have psychological need which affects their ability to be self-caring. It is believed the Brighton service would benefit from expansion to provide cover for individuals at this level. Based on the recent survey of patients, one-to-one therapy (CAT) would benefit from extension to a four day per week provision. An audit of patients over the past five years also shows that an eating disorder group for patients would also meet patient need, as would psychological input in the intensive education sessions and weight management groups.

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Appendix A. Group membership

NAME	Role/Job Title	Organisation/Location
Fran Ackland	Consultant Paediatrician	Northampton General Hospital NHS Trust
Trudi Akroyd	YoC Project Lead; lead on psych/emotional support for C&K YoC. DSN background	Calderdale & Kirklees
Saima Ali	Research Fellow	University of Warwick
Ruth Allen	Consultant Clinical Psychologist in Primary Care	Tower Hamlets
Ursula Anderson	Regional Programme Manager	NHS Diabetes
Clare Beard	Programme Manager	NHS Diabetes
Christine Bundy	Senior Lecturer in Health Psychology/ Psychological Medicine	University of Manchester
Deborah Christie	Consultant Clinical Psychologist/Hon. Reader,	London Centre for Paediatric Endocrinology and Diabetes (UCL)
Neil Collins	Service user	
H. C Cooper		University of Chester
Lynne Day	Service user	
Kathryn Dennick Warwick.	Author of literature review	Warwick Medical School, University of
Barbara Elster	Service user and Diabetes UK VP	Ilford
Joan Everett	Diabetes Nurse Specialist	Bournemouth
Linda Gask	Academic - Professor of Primary Care Psychiatry, UoM	IAPT Salford Pilot lead
Janet Grant	Service user	Croydon
Michelle Greenwood	Regional Programme Manager	NHS Diabetes
Kail Gunaratnam	Service user	
Mark Hannigan	Commissioner- Strategic Service Development Manager – LTC Regional Programme Manager and national lead for Emotional and Psychological Support Lead	Leeds PCT NHS Diabetes
Khalida Ismail	Clinical Reader and Consultant Liaison Psychiatrist	Diabetes Centre, Kings College Hospital, King's Health Partners
Anna Jesson	Diabetes Education Facilitator	Cumbria PCT
Gillian Johnson	Acting Locality Lead Northumbria Diabetes Service	North Tyneside General Hospital
Suzanne Lucas	Diabetes Education Consultant	
Kumkum Misra	GP	Coventry
Simon O'Neill	Director of Care, Information and Advocacy, Diabetes UK	London
Suzanne Paylor Hannah Tait Stephanie Parker	DH Diabetes team - Policy Managers	London
Sian Rees	DH Mental Health Team - Senior Policy Advisor	London
Elaine Ross	GP	Coventry
Clare Shaban	Consultant Clinical Psychologist	Royal Bournemouth Hospital

NAME	Role/Job Title	Organisation/Location
Jackie Steadman	Nurse and Community Diabetes Team Manager – special interest in CYP	IAPT Salford Pilot
Jackie Sturt	Academic – Senior Lecturer/Associate Professor in Behavioural and Social Sciences	University of Warwick
Rebecca Thompson	PDSN Clinical Nurse Specialist	London
Peter Trigwell	Consultant in Liaison Psychiatry Associate Medical Director	Leeds General Infirmary Leeds Partnerships NHS Foundation Trust
Stella Valerkou	Senior Policy Officer, Diabetes UK	London
Sandra Waddingham	Nurse and Diabetes Co-ordinator	North Lancashire PCT
Karen Walker	Programme Manager	Skills for Health
Maureen Wallace	GP	Coventry
Helen Wilkinson	Knowledge Manager	NHS Diabetes
Nicole de Zoysa	Clinical Psychologist Diabetes and Cardiac Rehab	Kings College Hospital

Appendix B. Other models of care

Triangular and stepped models have been used elsewhere in relation to the management of care, both in terms of psychological support, and the management of long term conditions.

Kaiser Permanente, a non-profit health maintenance organisation, has developed what has come to be known as the 'Kaiser Triangle' (Figure B1). This model enables the needs of people with long term conditions to be mapped onto the triangle, giving an indication of the types of services required to support an individual at each level.

Figure B1 The Kaiser Triangle¹⁵¹



The Kaiser triangle represents a continuum of need. Care is integrated across disciplines and organisations, including primary and secondary care. A population management approach with a combined emphasis on prevention, self-management and disease management is delivered appropriately at each level of need. This model has been associated with improvements in quality of life and admissions to, and length of stay in, hospitals in the USA. Preliminary case study data in the UK indicate positive effects.¹⁵²

The NHS and Social Care long term conditions model, which has drawn inspiration from the Kaiser model, also matches a person with diabetes needs to the care provided, informed by a triangular model. The majority of people with diabetes are defined as being at low risk are

supported to self-care, and the minority, defined as high intensity users of unplanned secondary care, receive case management by community matrons or equivalent professionals.¹⁵³

The stepped model used by the National Institute of Health and Clinical Excellence (NICE)¹⁵⁴ in their guidance on depression, in long term physical health conditions aims to match people with diabetes with the most appropriate service depending on their level of emotional and psychological need, which is mediated by personal, social and illness-related circumstances (Figure B2). Those responsible for care range from generalist healthcare professionals supported by psychological specialists, to mental health specialists with increasing severity of need.

¹⁵¹ Ham (2003, 2006), Singh and Ham (2006)

¹⁵² Ham (2003, 2006), Feachem et al (2002), Singh and Ham (2006)

¹⁵³ Department of Health (2007c)

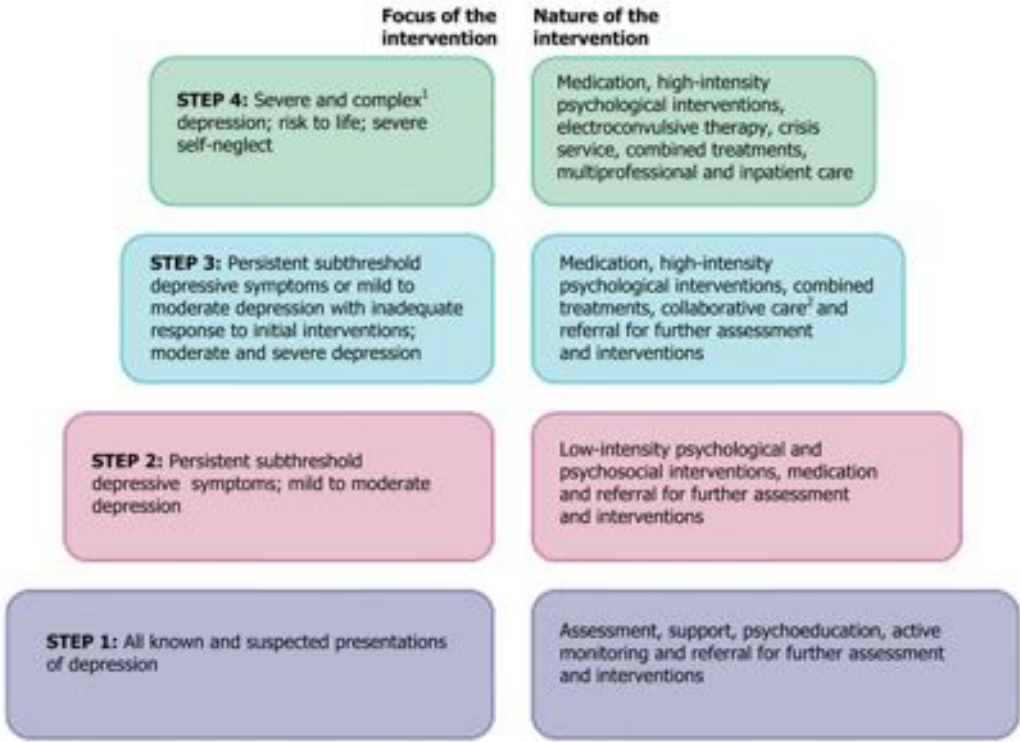
¹⁵⁴ NICE (2009)

NICE has also developed a model for palliative care that matches level of need with the type of assessment required, relevant interventions and the professionals and skills required to deliver these.¹⁵⁵

The IAPT programme uses a model of stepped care in which all people with diabetes are routinely monitored at every contact and treatment is

‘stepped up’ with increasingly complex intervention if previous attempts are unsuccessful and emotional and psychological need is raised. Each ‘step’ requires a different level of psychological therapy skills to match emotional and psychological need, reflected in a mix of appropriately trained personnel.

Figure B2. The National Institute of Health and Clinical Excellence stepped care model for the management of depression in adults and adults with a chronic physical health problem.¹⁵⁶



¹ Complex depression includes depression that shows an inadequate response to multiple treatments, is complicated by psychotic symptoms, and/or is associated with significant psychiatric co morbidity or psychosocial factors.

² Only for depression where the patient also has a chronic physical health problem and associated functional impairment.

¹⁵⁵ NICE (2004)

¹⁵⁶ NICE (2009)

Appendix C. Workforce resources

These resources are directly applicable to workforce skills, knowledge and competences for the pyramid model. Skills for Health (SFH) have started the process and it continues with links to other professional standards for knowledge, accreditation and refresher or Continuing Professional Development (CPD) requirements and can be applied at all levels. This non-exhaustive list contains major components for commissioners and providers to examine the requirements within their own services.

Skills for Health

Skills for Health has a database of national workforce competences and national occupational standards (NOS) relevant to the entire spectrum of diabetes care from diagnosis to the management of long term complications.¹⁵⁷

This can be accessed at <https://tools.skillsforhealth.org.uk/suite/show/id/40> published on the website these are subject to periodic review and update.

National Occupational Standards (NOS), for psychological therapies focusing on the following four therapy areas have been developed:

- Cognitive Behaviour Therapy
- Psychodynamic Psychotherapy
- Systemic and Family Therapy
- Humanistic Therapy

The final NOS have been submitted and are awaiting approval by the UK Commission for Employment and Skills. Once approved these will be available on the SFH website at; <http://www.skillsforhealth.org.uk/competences/completed-competences-show-hide.aspx>

A range of resources to support the role of commissioners in workforce planning is available from <http://www.healthcareworkforce.nhs.uk/capabilityandcapacitycommissioners.html>

Further information on the Six Steps Methodology to Integrated Workforce Planning can be found at

http://www.healthcareworkforce.nhs.uk/resource_library/latest_resources/six_steps_refresh.html

Other Sources

British Psychological Society National Occupational Standards for Psychology
[http://www.bps.org.uk/document-download-area/document-download\\$.cfm?file_uuid=B5649668-1143-DFD0-7E2C-D2987DA035BF&ext=pdf](http://www.bps.org.uk/document-download-area/document-download$.cfm?file_uuid=B5649668-1143-DFD0-7E2C-D2987DA035BF&ext=pdf)

http://www.bps.org.uk/dcp-facchp/policy-matters/policy-matters_home.cfm

Royal College of Psychiatrists: Competency based curriculum for specialist training in psychiatry - specific module in Liaison Psychiatry

http://www.pmetb.org.uk/fileadmin/user/QA/Curricula/Approved_curricula/Psychiatrists/Liaison_Feb09.pdf

Department of Health: The competences required to deliver effective cognitive and behavioural therapy for people with depression and anxiety disorders
<http://www.skillsforhealth.org.uk/competences/completed-competences-show-hide.aspx>

British Association for Counselling and Psychotherapy: Ethical Framework for Good Practice in Counselling and Psychotherapy
http://www.bacp.co.uk/ethical_framework/

British Association for Behavioural and Cognitive Psychotherapies
<http://www.babcp.com/members-accreditation/>

Improving Access to Psychological Therapies: Competency framework and assessment tools.
<http://www.iapt.nhs.uk/2008/01/01/cognitive-behavioural-therapy-competences-framework/>

http://www.ucl.ac.uk/clinical-psychology/CORE/CBT_Framework.htm#Description

Training by a MINT approved trainer to ensure Motivational Interviewing skills
<http://motivationalinterview.org/training/mint.htm>

¹⁵⁷ Skills for Health (2009)

Appendix D. Health inequalities

The Working Group commissioned a review of relevant literature on health inequalities and emotional wellbeing. The literature review focused on Black Asian and Minority Ethnic (BAME) communities, people with learning disabilities, people from travelling and gypsy communities and people in prisons, consistent with work areas being undertaken by Diabetes UK. Research undertaken by the specialist research agency Ethnic Focus was commissioned and consisted of three focus groups conducted with people from the Polish community newly arrived in the UK, people with learning disabilities and people from a travelling and gypsy community. Each group had between 8 and 10 participants. This appendix summarises the findings from both these sources of evidence.

It is clear from the evidence presented here that people with diabetes must be involved in the design of local diabetes services, including people from communities that are known to experience health inequalities and whose needs may be seldom heard. The findings are not meant as generalisations but to illustrate some of the factors that can create inequalities in emotional and psychological need and barriers to accessing appropriate interventions; along with some potential approaches to solutions.

People with Learning Disabilities

The prevalence of diagnosable psychological conditions amongst people with learning disabilities is 14.4 per cent for people with mild to moderate learning disabilities, and 18 per cent for people with severe learning disabilities, in England and Wales. The literature points to an elevated prevalence of some psychological conditions such as schizophrenia and phobic disorder, in people with learning disabilities.¹⁵⁸

There is also evidence that young people with learning disabilities experience more emotional and psychological problems than their peers without learning disabilities.¹⁵⁹ Factors associated with inequalities in emotional and psychological need experienced by people with learning disabilities include socio-economic disadvantage, physical disability, familial problems¹⁶⁰ and social distress.¹⁶¹

In some cases, a desire to address emotional and psychological need within the family and the underestimation of this need by family members has also presented a barrier to people with learning disabilities who need to access emotional and psychological support services.¹⁶²

Interventions to meet the emotional and psychological needs of people with learning disabilities are poorly developed at present. There is recognition that interventions developed for people without learning disabilities are unlikely to meet the needs of those who have them.¹⁶³

The need for an integrated approach to service delivery with collaboration across various service providers is highlighted as vital to ensuring individuals receive high quality support.¹⁶⁴

The focus group conducted with people with moderate learning disabilities identified the role of carers and visiting health professionals in providing health information and support in accessing services. Carers and day care workers were also seen as a source of support. Face to face support and the opportunity to receive peer support from other people with diabetes were identified as valuable by the focus group participants. A variety of sources of information were seen as valuable such as pictorial, DVD or video-based information as well as face to face delivery. Day care centres were cited as useful venues for the provision and dissemination of information.

¹⁵⁸ Deb, S., Thomas, M. & Bright, C. (2001)

¹⁵⁹ Kolaitis, G. (2008).

¹⁶⁰ Deb, S., Thomas, M. & Bright, C. (2001)

¹⁶¹ McGillivray, J.A. & McCabe, M.P. (2007).

¹⁶² Havercamp, Scandlin & Roth, (2004); Kolaitis, (2008).

¹⁶³ Dagnan, D. (2007).

¹⁶⁴ Kolaitis, G. (2008).

Gypsies and travellers

Research has shown UK and Irish gypsies and travellers experience more difficulties with anxiety and depression, and experience worse health related quality of life than non gypsies and travellers. Between 18 -25 per cent experience moderate anxiety or depression and 5 -12 per cent experience severe manifestations of these conditions.¹⁶⁵

Despite these findings, at the time the evidence was presented a number of gypsies and travellers were awaiting access to secondary psychiatric services. Inequalities in emotional and psychological need appear to be related to a complex interaction of a number of socioeconomic factors including; lack of employment opportunities, financial hardship, social isolation and living conditions. Furthermore discrimination, exclusion and harassment by the settled population and a loss of identity when forced to settle in housing also contribute to these inequalities.¹⁶⁶

Gypsies and travellers also experience inequalities in accessing emotional and psychological support. Evictions can result in the crossing of geographical boundaries as people move, and this and missed appointments can result in untreated non urgent conditions. The lack of understanding about gypsy and traveller culture amongst healthcare professionals, and a lack of permanent address can be obstacles to enabling gypsies and travellers to register with GP practices. Health can also compete as a priority with other practical concerns, and familial or cultural stigma associated with mental illness can also act as a barrier. The provision of health information that requires a high level of literacy can also present a barrier for some gypsies and travellers.¹⁶⁷

The need for culturally appropriate mental health services is evident, including the following points for consideration:¹⁶⁸

- Collaboration is needed between healthcare and mental health professionals, and providers who have already established relationships with gypsy and travelling communities.

- The training of peers to provide a level of support and liaison with appropriate services.
- Specialised Health Visitors could have a role as advocates at a national level.
- Consideration should also be given to family based interventions.

Focus group participants echoed some of the findings within the literature, and in particular raised similar points to the first three bullet points above. One of the themes emerging from the focus group was experiences of prejudice and stigmatisation and a feeling of not being taken seriously. These experiences created very significant barriers to accessing healthcare. Anxieties were raised both about knowing how to manage diabetes and about continuity of care. Accident and Emergency departments were used by some participants when it was felt that accessing routine care was problematic or waiting times were too long.

When considering the development of information, a range of formats and avenues for dissemination were suggested, and particularly the need to take literacy levels into consideration. The use of videos/ DVDs, pictorial information and face to face delivery were all mentioned.

It was highlighted that work is needed to dispel myths about the travelling community, and good practice guides for healthcare professionals in working with the travelling community would be beneficial. Involving health visitors and people from the travelling community with diabetes in delivering health messages and providing support were also suggested. Peer support from other travellers was seen as valuable, with the ideas of both seeking out support from within the travelling community, but also of being open to receiving support from healthcare professionals.

People in prisons

A higher rate of mental ill health and suicide is present within the prison population than in the general population.¹⁶⁹ Several factors contribute to

¹⁶⁵ Goward, P., Repper, J., Appleton, L., & Hagan, T. (2006), Parry, G., Van Cleemput, P., Peters, J., Walters, S., Thomas, K., Cooper, C. (2007). Van Cleemput, P. & Parry, G. (2001).

¹⁶⁶ Goward, P., Repper, J., Appleton, L., & Hagan, T. (2006), Parry, G., Van Cleemput, P., Peters, J., Walters, S., Thomas, K., Cooper, C. (2007). Van Cleemput, P. (2000).

¹⁶⁷ Goward, P., Repper, J., Appleton, L., & Hagan, T. (2006), Parry, G., Van Cleemput, P., Peters, J., Walters, S., Thomas, K., Cooper, C. (2007). Van Cleemput, P. (2000).

¹⁶⁸ Goward, P., Repper, J., Appleton, L., & Hagan, T. (2006), Van Cleemput, P. (2000).

¹⁶⁹ All Parliamentary Group for diabetes and Diabetes UK(2006), Reed, J. (2003).

this including reduced contact with family members, extensive periods of isolation, negative relationships with staff, bullying from other inmates and little mental stimulation.¹⁷⁰

Transfers from one institution to another can also disrupt continuity of care, particularly where an individual's healthcare records are not appropriately transferred. Despite a Department of Health and Prison Service strategy for improving mental health services in the prison setting, health inequalities and limitations with regard to the healthcare system persist.¹⁷¹

Black and Minority Ethnic communities

The emerging literature into emotional and psychological aspects of diabetes in culturally diverse groups has largely focused on the prevalence of common mental disorders, particularly depression. Much of this research has focused on minority groups with diabetes in the USA, including African American, Latino and Asian American groups and has demonstrated similar or elevated risks of self-reported depressive symptoms in comparison to non BME groups.¹⁷²

Furthermore preliminary findings in people with diabetes suggest that African Americans have higher rates of unrecognised depression, are less likely to discuss depression with their primary care provider and are less likely to receive any form of treatment for depression in comparison to their White counterparts.¹⁷³ Possible reasons for these disparities may include a greater preference for spiritual healers,¹⁷⁴ cultural differences in beliefs about the causes and treatment options for depression which in turn may affect help seeking,¹⁷⁵ as well as barriers

associated with community stigma and provider mistrust.¹⁷⁶

Data regarding emotional and psychological aspects of diabetes in BME groups in the UK however is scarce, although two recent studies have focused on ethnic differences in the prevalence of depression between South Asian and White Europeans with diabetes. The first of these studies identified lower rates of diagnosed depression (based on a coded diagnosis or antidepressant prescribing data) in South Asians attending a hospital diabetes clinic in comparison to their White European counterparts.¹⁷⁷

A second study also examined the prevalence of depression in South Asian and White European people with Type 2 diabetes in primary care as well as ethnic differences in the recognition of depression.¹⁷⁸ Findings from this study revealed higher rates of screen detected depression in South Asians with diabetes in comparison to White Europeans, however rates of recognised depression (as assessed by patient medical records) revealed considerably higher rates of under-diagnosis in South Asians with diabetes, even when factors such as deprivation and co-morbid conditions were taken into account. It is likely that higher levels of emotional and psychological problems in BME groups may in part be explained by inequalities in terms of access to culturally appropriate diabetes-related educational support.¹⁷⁹ Lower levels of knowledge and inappropriate health beliefs about diabetes and its management may also impair efforts to self-manage which in turn may lead to emotional and psychological problems.¹⁸⁰ Cultural issues may also present a number of diagnostic challenges when identifying common mental disorders including depression in BME groups,¹⁸¹ for example difficulties may be faced due to differences in the

¹⁷⁰ Nurse, J., Woodcock, P. & Ormsby, J. (2003).

¹⁷¹ Reed, J.L. & Lyne, M. (2003). Department of Health (2001c).

¹⁷² Wagner J, Tsimikas J, Abbott G, de Groot M, Heapy A. (2007). Jackson-Triche ME, Greer-Sullivan J, Wells KB, Rogers W, Camp P, Mazel R: Black SA, Markides KS: De Groot M, Lustman PJ: Li C, Ford ES, Strine TV, Mokdad, AH. (2006).

¹⁷³ Wagner JA, Perkins DW, Piette JD, Lipton B, Aikens JE. (2009).

¹⁷⁴ de Groot M, Pinkerman B, Wagner JA, Hockman A. (2006), Egede LE. (2002).

¹⁷⁵ Cooper-Patrick L, Powe NR, Jenckes MW, Gonzales JJ, Levine DM, Ford DE. (1997).

¹⁷⁶ Egede LE. (2002).

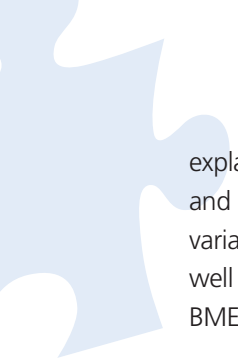
¹⁷⁷ Ali S, Davies MJ, Taub NA, Stone MA, Khunti K. (2009).

¹⁷⁸ Ali S, Taub NA, Stone MA, Davies MJ, Skinner TC, Khunti K (2009).

¹⁷⁹ Alam R, Singleton L, Sturt J (2008), Greenhalgh PM (2004).

¹⁸⁰ Fisher L, Chesla CA, Mullan JT, Skaff MM, Kanter RA (2001).

¹⁸¹ Ahmed K, Bhugra D. (2007).



explanatory models between people with diabetes and health care professionals, linguistic barriers, variation in the clinical presentation of symptoms as well as a lack of validated screening tool for use in BME communities.¹⁸²

These issues may be further complicated due to barriers in help-seeking behaviour among members of BME groups, as a result of perceived social stigma and service or provider mistrust.¹⁸³ However it is also important to consider that research findings from members of some BME groups cannot be generalised to all individuals as there may be wide variations in socioeconomic factors, health beliefs, levels of acculturation as well as religious practices and beliefs. There is also likely to be variation in the prevalence of specific emotional and psychological problems and what may be considered to be acceptable forms of treatment in one ethnic group may conflict with the ideas and beliefs of another- even amongst those who have traditionally been classified together (e.g. Indian communities may include Hindu, Sikh and Muslim religious subgroups who may vary in terms of their ideas and beliefs regarding the causes of emotional and psychological problems which in turn may influence help-seeking behaviour and preferences for treatment).

These findings highlight the need for improved patient-provider communication in regards to probing for emotional and psychological issues, discussion regarding the aetiology as well as different treatment options for diverse populations with diabetes. The Department of Health and other stakeholders are currently developing a programme which demonstrates a commitment to provide culturally responsive services for BME communities and to achieve equality in mental

health; the Delivering Race Equality in Mental Healthcare programme¹⁸⁴ involves a five year action plan for tackling the inequalities and discrimination in mental health services experienced by all BME communities in England. The action plan is based on three building blocks of reform which include the development of better more responsive services, better engagement of services with their local communities and better information.¹⁸⁵

A focus group was conducted with members of the Polish community newly arrived in the UK. Experiences of the healthcare system in Poland influenced opinion about services in England for some focus group participants. Where knowledge of the English language was limited, intermediaries such as friends or relatives who speak English might be used as a support to access health care services.

Anxieties about facing discrimination in the work place and losing employment as a result of having diabetes were raised, and linked to this, issues regarding having appropriate facilities to administer medication whilst at work. The need for information in a variety of formats, including written materials available in different languages was highlighted, as well as the use of translators. The dissemination of information in Polish shops, magazines and community centres was suggested and the Job Centre was mentioned as a place where health information was also sought.

Opportunities for peer support from other people with diabetes, was seen as valuable. It was also identified that families were not always a source of emotional support, as they may not always have an understanding of diabetes.

¹⁸² Ahmed K, Bhugra D. (2007).

¹⁸³ Shaw CM, Creed F, Tomenson B, Riste L, Cruickshank JK (1999), Fogel J, Ford DE. (2005), Ahmed K, Bhugra D. (2007).

¹⁸⁴ Department of Health (2005b)

¹⁸⁵ Department of Health (2005b)

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