



Tower Hamlets Mental Health Strategy Supporting Document – Evidence reviews

August 2013

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PREVENTION AND EARLY INTERVENTION: A REVIEW OF THE LITERATURE

Scope

The literature review aimed to answer the following questions:

1. What does the evidence say are effective approaches to promoting mental health and wellbeing in children and young people?
2. What does the evidence say are effective approaches to the management of conduct disorder in young people?
3. What does the evidence say are effective approaches to early intervention in psychosis?
4. What does the evidence say are effective approaches to improving the experience of people with mental health problems of primary care services?
5. What does the evidence say are effective interventions are the effective interventions to support patients with a co-morbid substance misuse problem (including alcohol and including consideration across the life course)?
6. What does the evidence say are effective interventions to support people with a mental health problem who are in the criminal justice system, including in the Youth Justice system?
7. What does the evidence say are effective approaches to tackling loneliness?
8. What does the evidence say are effective approaches to preventing suicide?

Introduction

The Royal College of Paediatrics and Child Health have stated that “*mental disorders in children and young people are increasing and represent a hidden epidemic*”¹. The implications for the children and young people affected and their families are significant; with potential implications for education, personal relationships, and involvement in crime and anti-social behaviour, future employment and physical health. Prevention of mental disorders in children and young people is an important public health measure to avoid the long term serious health and social related consequences.

Promoting the mental health and wellbeing of children and young people is a central part of the policy agenda set out by the Department of Health and the Department for Education in the recent *No Health without Mental Health Strategy*². A strong element of the approach is ensuring good maternal health (including mental health).

The statistics about Children and Young People and Mental Health give some context to the challenge: around half of all mental health disorders appear during childhood and early adolescence. 75% of mental disorders begin before the age of 25 years and a substantial number (50%) become apparent before the age of 14 years.³ As a result of the severity and

¹ PCPCH (2010). Accessed at: http://www.bpmhg.org.uk/wp-content/uploads/2012/01/Mental_health_s_C0F9B2.pdf July 2013

² Centre for Mental Health, Department of Health, Mind, NHS Confederation Mental Health Network, Rethink Mental Illness, Turning Point (24 July 2012). No Health without Mental Health. Accessed at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/156084/No-Health-Without-Mental-Health-Implementation-Framework-Report-accessible-version.pdf. July 2013.

³ Birleson, P. and Vance, A. Developing the youth model in mental health services. *Royal Australian and New Zealand College of Psychiatrists*. 2008; vol 16:1

complexity of the implications of mental ill health there is also a building economic case for prevention and early intervention both in terms of the cost to the Health Service as well as the impact on the economy⁴.

Methods

A systematic search was conducted using of seven electronic databases to identify relevant studies – PsycINFO, MEDLINE, HMIC, EMBASE, BNI, AMED, and CINAHL. In addition, a search engine was used to identify any relevant reports and research studies conducted by relevant third sector organisations and government departments. The draft review was reviewed by a number of external professionals who also recommended studies. These were additionally added.

Search terms included: mental disorders; prevention/ or primary mental health prevention; biological family/ or dysfunctional family/ or extended family/ or family/ or family background/ or family conflict/ or family intervention/ or family members/ or family therapy; aging/ or elder care; racial and ethnic groups; child; family/ or family health/ or family therapy; preventative measures; secondary prevention/ or prevention study; older adult care; family/ or extended family/ or dysfunctional family/ or family centered care/ or family counseling/ or family interaction/ or family theory/; nursing/ or elderly; aged/ or geriatric assessment.

The searches were conducted in December 2012.

Definitions

The theory of prevention illustrates that there are several different levels of prevention activity. This part of the literature review primarily focuses on *Primary Prevention* which seeks to reduce the incidence of mental health problems. There are two other levels of prevention which are *secondary prevention* that seeks to reduce the length of active illness and the severity of symptoms and *tertiary prevention* seeks to reduce the mortality of the illness and future relapses. This literature review focuses on primary prevention.

Primary prevention itself can be split into three further “levels” outlined below:

- *Universal preventive* interventions are targeted to the whole population and do not include an identification of individual risk; i.e. those integrated within school curricula. These types of programmes focus “on the enhancement of general social/emotional and cognitive skills that can alleviate different behaviours disturbances, including mood and anxiety problems” (TH Public Health).
- *Selective prevention* targets individuals or sub groups at significantly higher risk of developing mental disorder as evidenced by biological, psychological or social risk factors.
- *Indicative prevention* targets high risk people as identified as having detectable signs of mental disorder or markers indicating predisposition.⁵

⁴ Mental Health Network – NHS Confederation, 2011, Key facts and trends in Mental Health: Updated figures and statistics, available at: http://www.nhsconfed.org/Publications/Documents/Key_facts_mental_health_080911.pdf

⁵ Marlowe, K., 2011, Prevention of Mental Illness – internal slides

Findings

1. What does the evidence say are effective approaches to promoting mental health and wellbeing in children and young people?

Predicting factors

Severe marital discord, low socio economic status, overcrowding or large family size, paternal criminality, maternal psychiatric disorder and foster home placement of children in the family have been identified with increased psychiatric disorder in children⁶. Children of parents with mood or anxiety disorders are themselves at risk of developing similar disorders⁷.

Mental Health problems in children can manifest themselves as “externalising behaviour” problems (aggression and oppositional defiance) and internalising behaviour problems (anxiety and depression). Research has found that the common risk factors for externalising and internalising problems are physical health problems; difficult temperament and insecure attachment related behaviours. The family risk factors are parental mental health problems (depression), separation/divorce, daily hassles and controlling parent style⁸. Risk factors specific to externalising problems are male; siblings, young and low educated parents, marital problems, poor social support, low parent efficacy, harsh discipline and use of poor quality child care services. Risk factors specific to internalising problems are temperamental inhibition, parent illness/death, parental anxiety and over protective parenting.⁹

From Bayer’s research in Australia, parental stress and harsh discipline were predictors of early childhood externalising difficulties whilst parent stress and anxiety were risks for internalising difficulties. This work, as well as other evidence highlighting predicting and risk factors shows that promoting the mental health of children and young people needs to include a focus on the wider family and social context.

Protective Factors

Coping, the ability to regulate emotions and behaviour in the face of stress can protect against the negative effects of stress and is more amenable to intervention.¹⁰ Primary control coping includes problem solving and emotional regulation whereas secondary control coping includes cognitive restructuring and positive thinking. Both primary and secondary control coping are associated with improved psychological adjustment in children and adolescents exposed to a variety of uncontrollable stressors (e.g. illness, family conflict)¹¹. The research, conducted by Raviv and Wandsworth on a four week pilot prevention program showed that primary and secondary control coping can “buffer” children against the stresses that poverty and economic stress causes (both of which are risk factors to child psychopathology). The research also showed that children’s ability to generate positive coping thoughts and high

⁶ Bond, L.A. and Joffe, J.M. (Eds). (1982). Facilitating infant and early childhood development. New England Press.

⁷ Opler, Mark; Sodhi, Dimple; Zaveri, Deval; Madhusoodanan, Subramoniam. Primary psychiatric prevention in children and adolescents. 2010 Nov;22(4):220-34, Annals of clinical psychiatry. 2010, vol: 22, page: 220

⁸ Bayer et al, 2008, “Early Childhood Aetiology of Mental Health Problems: A Longitudinal Population Based Study” in Journal of Childhood Psychiatry, vol 49, 11

⁹ Ibid

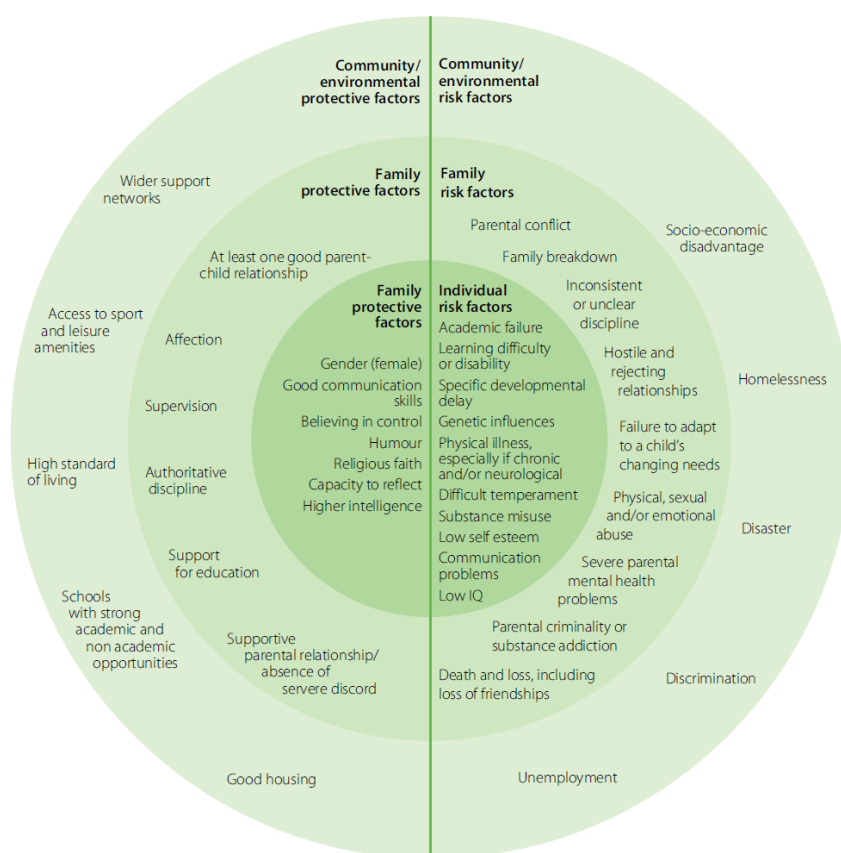
¹⁰ Raviv, T. and Wadsworth., M., (2010), “The efficacy of a pilot prevention programme for children and caregivers coping with economic strain” in Cognitive Therapy and Research, Vol 34, 3

¹¹ Ibid

quality solutions to problems improved from pre- to post-intervention. From this research, supporting the development of effective coping mechanisms in children and young people was recommended to protect children and young people from developing mental ill health.

Social support systems (including friends, family, school, and environment) can also be “protective factors” against the development of a mental health problem. To support children and young people build social support systems involves the parent-child relationship, family based interventions and school based support. Figure 1 illustrates risk and protective factors in a child or young person’s life. The relationship between risk and protective factors is complicated but a young person with the same risk factors with a strong level of protective factors is likely to respond more resiliently to challenges/crises than a young person without them.

Figure 1. Risk and protective factors



Source: DCSF, 2010

Parental Mental Health

A risk factor for children and young people developing mental ill health is that their parents suffer from mental ill health (illustrated in figure 1). The impact of parental mental ill health may be reduced though if protective factors are increased. For example, those who have chronically ill parents may benefit from group discussions with similar aged children (peer support) through developing feelings of acceptance and developing positive self-identity. Psycho education programs about different types of mental illness the impacts it can have on parenting and family relationships as well as the development of coping skills can all

support children and young people build their protective factors against mental ill health¹². Such approaches would aid other interventions including parental training, universal school support, etc. More information on parental mental health can be found in the family and carers literature review.

Family/Parent Training

Parenting style is a “strong determinant of a child’s behaviour and self-image, and interventions that promote a more positive parenting style can be used to improve behavioural problems in children and young people”¹³. As a result “promoting positive mental health in childhood is therefore closely bound up with the promotion of positive parenting”.¹⁴

Targeted programmes at families at risk, support provided through home visiting to disadvantaged families and programmes targeted at teenage mothers have all been shown positive results on either, measures of child behaviour, the quality of mother-child interactions or maternal confidence. Additionally a number of economic studies have shown that parenting support can be highly cost effective when targeted at disadvantaged families or at the parents of children with identified problems. The types of support included in this analysis are home visiting, day care and education for parents and teachers of those children with identified problems¹⁵. Cost effective evidence for less targeted approaches is not as clear as long term benefits are more difficult to fully analyse and understand.

The Department of Health and the Department of Education have acknowledged the importance of investing in parenting programmes in the recently published national strategy entitled “*Supporting Families in the Foundation Years*”. Whilst there is good take up of antenatal groups amongst first time parents this is not the case for parenting programmes which have been shown to improve outcomes for families. The strategy notes that parenting programmes have been shown to improve adolescent mental health problems as well as other outcomes including parental wellbeing. The Government however has not set out a prescribed approach to commissioning such support and rather states that they need to meet local needs whilst operating within a national framework.¹⁶

However, as highlighted earlier, in general targeted programmes are shown in the evidence to be more cost effective, but it is arguably those young people at risk that are the most difficult population for family prevention to address. Parents in the highest-risk groups may be the least likely to access family based programmes. Evidence from Hogue *et al.* (2002) highlights that these programmes should focus on parent-child interaction skills, establishment of an appropriately egalitarian parent-child relationship and attention to the unique perspective and autonomy needs of the young person. Through children and young people being actively involved in family programmes, families can support each other when developing coping strategies to manage and deal with crises.¹⁷

¹² Tower Hamlets Public Health. Primary, secondary and tertiary prevention of mental ill health – effective interventions for children, young people and families.

¹³ Licence, K., 2004, “Promoting and protecting the health of children and young people” in *Child: Care health and development*, vol. 30, issue 6

¹⁴ Ibid

¹⁵ Ibid

¹⁶ Department of Education and the Department of Health (2011). *Supporting Families in the Foundation Years*

¹⁷ Hogue, A., Liddle H.A., Becker, D., Johnson-Leckrone, J. Family-based prevention counseling for high-risk young adolescents: immediate outcomes. *Journal of Community Psychology*. 2002, Vol. 30, No. 1, 1–22 (2002)

Role of schools

Evidence strongly supports social and emotional learning programmes that include social problem solving, social awareness and emotional literacy. These programmes have been shown to be most effective as part of a whole school approach to promoting health and wellbeing. Whole school approaches include: classroom teaching elements, teacher training, and parental involvement. The overall ethos and principles that underpin the school environment are also critical.

School based Social and Emotional Learning (SEL) programmes help children and young people to recognise and manage emotions, set and achieve positive goals, appreciate the perspectives of others, establish and maintain positive relationships, make responsible decisions and handle interpersonal situations constructively. International evidence shows that SEL participants demonstrate significantly improved social and emotional skills, attitudes, behaviour, and academic performance. The results show that the SEL intervention is cost saving overall after the first year, while education recoups its costs in five years. A key driver of net savings is the crime related impacts of conduct problems that can be avoided.¹⁸

Social and emotional learning programmes: an explicit programme covering social problem-solving, social awareness and emotional literacy can be effective on its own, but most effective programmes take place within a whole school approach to promoting, mental health, wellbeing and positive behaviour. Evidence cited in Licence (2004)¹⁹, cites that school-based mental health promotion projects are most successful when they take a “whole school” approach and are sustained for a continued period of time.

A “whole school” approach includes all staff as well as children and young people themselves. As Knapp cites whole school approaches should focus on positive mental health which encompass the development of “coping mechanisms” to build the resilience of children and young people. There are a number of international examples of school based mental health initiatives for children and young people including “KidsMatter” in Australia for primary school children²⁰, “Zippy’s Friends” for 6-7 year olds²¹, “The Gatehouse Project” in Secondary Schools²² and “MindMatters”²³ both in Australia. From research studies investigating these approaches there’s recognition that schools and learning environments are complex systems subject to change and that the success of programmes is affected by the ability to sustain them within the schools capacity. From MindMatters teachers need to be comfortable and confident in promoting and teaching for mental health. Research highlights the role of schools in universal provision as well as their role in practical support including supporting referral pathways, monitoring child development and liaising with

¹⁸ Knapp, M *et al.*, (2011). Mental health promotion and mental illness prevention: The economic case

¹⁹ Licence, K., (2004). Promoting and protecting the health of children and young people. *Child Care health and Development*, vol. 30, issue 6

²⁰ Graetz *et al.*, 2008, “KidsMatter: A population health model to support student mental health and wellbeing in primary schools” in *International Journal of Mental Health Promotion*, vol 10, issue 4

²¹ Bale *et al.*, (2004). Developing an International Mental Health Promotion Programme for Young Children. *International Journal of Mental Health Promotion*, vol 6, 2

²² Patton, C. *et al.*, (2000). The Gatehouse Project: a systematic approach to mental health promotion in secondary schools. *Australian and New Zealand Journal of Psychiatry*, 34: 586-593

²³ Wyn, *et al.*, (2000). MindMatters, a whole school approach to promoting mental health and wellbeing. *Australian and New Zealand Journal of Psychiatry*, vol 34, pp 594-601

parents and other parts of the system (i.e. health services). Nevertheless there are barriers for schools in delivering mental health initiatives, these include:

- Lack of system support;
- Leadership;
- Staff turnover;
- Access to resources; and
- Access to professional development.

These findings highlight that despite schools having a key role to play in supporting and developing good mental health amongst children and young people that they require a significant amount of support to deliver population health models in practice. Graetz *et al.*²⁴ note the following resources as needed:

- A conceptual framework that provides an accessible ‘big picture’ overview including the rationale, likely benefits and some clear achievable goals;
- An implementation process that provides step-by-step guidelines geared to addressing those factors known to support implementation and maintenance of school-based mental health initiatives; and
- Key resources such as staff training, on-going project officer support and access to evidence-based programs.

The wider school and learning environment have also been shown to be important to promoting the mental health of children and young people. Licence (2004)²⁵ cites that “there is some evidence that exercise and outdoor pursuits programmes may contribute to short-term improvements in children’s self-esteem”.

Adelman and Taylor (2006) drew attention to another part of school based mental health promotion; the mental health and wellbeing of teachers and staff. A whole school approach to mental health and wellbeing promotion includes supporting staff (like pupils/students) to build resilience and ability to cope (coping mechanisms). As they stated “staff and students must feel good about themselves if they are to cope with challenges proactively and effectively”.²⁶

Targeted Mental Health in Schools (TaMHS)

In the UK there has been a national evaluation of the TaMHS programme. The aim was that TaMHS would help schools deliver timely interventions and approaches in response to local need that could help those with mental health problems and those at increased risk of developing them²⁷. From the evaluation the programme was particularly successful in decreasing over time behavioural problems in schools, further discussed in the conduct disorder literature review. In both primary and secondary schools there was a decrease in pupil self-reported emotional difficulties over the three year programme.

²⁴ Graetz *et al.*, (2008). KidsMatter: A population health model to support student mental health and wellbeing in primary schools. *International Journal of Mental Health Promotion*, vol 10, issue 4

²⁵ Licence, K. (2004). Promoting and protecting the health of children and young people. *Child Care health and development*, vol 30, issue 6

²⁶ Adelman, H. and Taylor, L., (2006). Mental Health in Schools and Public Health. *Public Health Reports*, vol 121

²⁷ UCL and Anna Freud Centre (2011). *Me and My School: Findings from the National Evaluation of Targeted Mental Health in Schools 2008-2011*. Available at: <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RR177#downloadableparts>

Interface between systems

Work by the Kings Fund exploring how primary schools are supporting children with emotional and behavioural needs highlighted that relationships and liaison between primary schools and destination secondary schools was important. In a couple of instances reported in the work parents had reported to staff that their child's emotional and behavioural needs unravelled quickly post the transition²⁸.

The Department of Health and the Department of Children, Schools and Families highlighted in 2009 that there was a need for better integration and information sharing between maternity services and the Healthy Child Programme team, school health teams and adolescent services, including child and adolescent mental health services (DH and DCSF, 2009) – the Common Assessment Framework and the Children and Families Partnerships locally facilitate partnership work and interface between systems.

Universal, selective or indicated prevention

Opler *et al* (2010)²⁹ have reviewed primary prevention programmes for mood and anxiety disorders amongst children and young people. The evidence suggests that each level of primary prevention has its role to play in preventing mental ill health.

Mood and anxiety disorders

From the review Opler found that universal programs focused around the school curricula (Interpersonal Cognitive Problem Solving Program) which support children to develop problem solving skills did reduce inhibition and impulsivity but 1 year on had not shown any reduction in psychiatric symptoms. However, when instructional interventions were included i.e. teaching about home and school environment (PATHS) this did lead to a decrease in externalising and internalising behaviours.

Selective prevention interventions in schools or learning environments that were reviewed showed higher levels of success, projects targeted at children with learning, emotional or social difficulties, at transition points (i.e. between primary and secondary schools) and with high risk families during pregnancy through to preschool years were effective at reducing anxiety and depression. Overall it was found that the majority of successful preventive programs focus on enhancing early mother and child bonding. Family based selective prevention for children of school age included projects that targeted those who had parents with a history of mood disorder, those whose parents were going through a divorce and those experiencing bereavement. The programs reviewed demonstrated reduced internalising scores, minimising behavioural or emotional problems or reducing depressive symptoms. A project working with adolescents with parents with a history of depression showed a decrease in the risk of depression following 15 sessions of group cognitive therapy.

A review of indicated prevention programmes (for those to minimal or mild depressive symptoms) demonstrated strong support for Cognitive Behaviours Therapy which was shown to decrease the incidence of depressive disorders.³⁰ The figure below presents a summary of the findings in relation to possible interventions matched risk factors.

²⁸ Lawton-Smith, S., (2007). Catching them early. Mental Health Today.

²⁹ Opler, Mark; Sodhi, Dimple; Zaveri, Deval; Madhusoodanan, Subramoniam. Primary psychiatric prevention in children and adolescents. 2010 Nov;22(4):220-34, Annals of clinical psychiatry. 2010, vol: 22, page: 220

³⁰ Ibid

Figure 2. Risk factors

Modifiable and nonmodifiable risk factors with possible interventions for mood and anxiety disorders in children and adolescents

Modifiable factors	Possible interventions	Nonmodifiable factors
Poor stress coping abilities	Promoting stress and anxiety coping skills Cognitive, emotional, and social skills enhancement	Parent with a mood/anxiety disorder
Poor social support system	Fostering the mother-child relationship, providing support, education and treatment (if essential) to the mother Family therapy sessions Enhancing school environment (make it one that is more supportive, promotes positive behavior, encourages teacher training)	Negative life events such as death of parents/parental divorce

Source: Opler et al (2010)

2. What does the evidence say are effective approaches to the management of conduct disorder in young people?

Conduct disorder is a common childhood psychiatric problem that has increased incidence in adolescence³¹. As with other mental health conditions it has a number of causes which include biological, psychosocial and family factors. Conduct disorders are defined as a repetitive and persistent pattern of dissocial, aggressive or defiant conduct³². In Tower Hamlets it is estimated that approximately 2,088 children and young people aged between 5 and 16 had a conduct disorder in 2011. This represents an estimated prevalence of 5.8% and in 2016 it is estimated that this will increase to 2,349³³.

Conduct problems that emerge in early childhood are likely to continue into adulthood, and they are also associated with a wide range of adverse long-term outcomes – including long standing adult mental illness, poor educational attainment, unemployment, impact on personal relationships, homelessness, criminality, substance misuse and poor physical health.³⁴ It is estimated that by the time they are 28 years old, individuals with persistent antisocial behaviour at age ten have cost society ten times as much as those without the condition.³⁵ Clearly, as with other mental health problems amongst children and young people it's both better financially and for children, young people and families to invest appropriately in support to prevent and identify early signs of conduct disorder. The below figure illustrates how the social context, parental factors and individual factors can impact behaviour and how that can then start to impact wider relationships – illustrating how such problems can be perpetuated throughout life.

Figure 3 shows the influences on antisocial behaviour seen at home and at school, and how the consequences may perpetuate it.

³¹ Searlight, H. *et al.* (2001). Conduct disorder: diagnosis and treatment in primary care. *American Family Physician*, vol 63, no 8

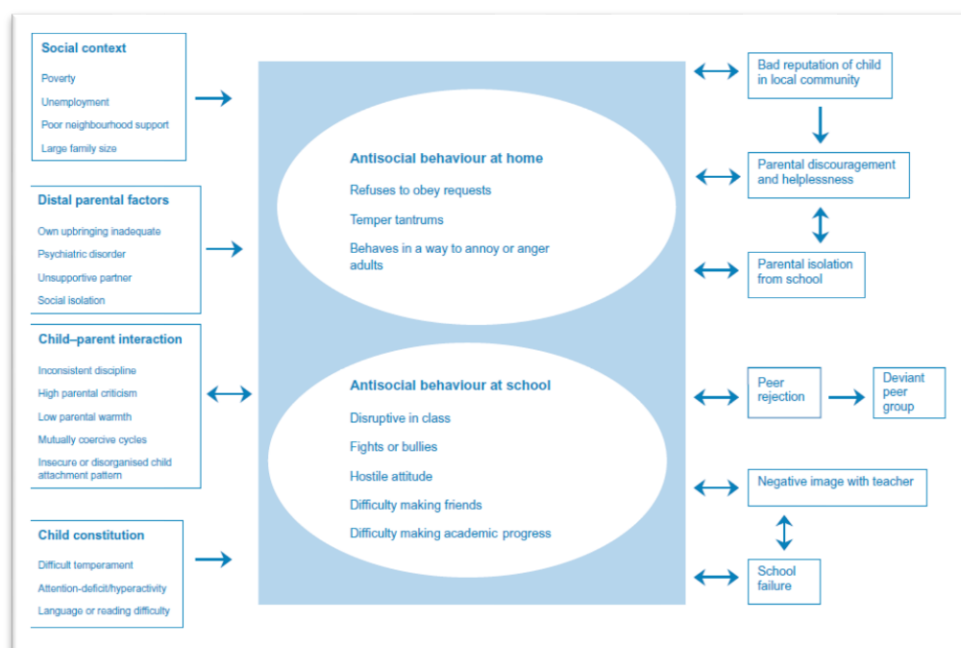
³² Boin *et al.* (2011). Costs and longer-term savings of parenting programmes for the prevention of persistent conduct disorder: a modelling study. *BMC Public Health*, vol 11

³³ Tower Hamlets (2011). Child and adolescent mental illness, mental health and emotional wellbeing Factsheet Tower Hamlets Joint Strategic Needs Assessment 2010-2011

³⁴ Brown, E., Khan, L. and Parsonage, M. (2012). Delivering effective parenting programmes to transform lives

³⁵ Scott, Knapp, Henderson and Maughan (2001). Financial cost of social exclusion: follow up study of antisocial children into adulthood. *British Medical Journal* 323: 191-194

Figure 3. Influences on antisocial behaviour and the consequences



Source: Spender, Q. and Scott, S. (1997). Management of Antisocial Behaviour in Childhood. *Advances in Psychiatric Treatment: Journal of Continuing Professional Development*, vol. 3, pp 128-137

Identification and referral

Schools and GPs are an important access point to parents with children who are worried about the behaviour of their children. It is therefore important that there is appropriate support to raise awareness of such conditions locally as well as support to enable effective signposting to specialist provision where appropriate.

Searlight *et al.* (2001) conclude that there are a number of interventions that “family practitioners” or GPs can do to support parental training for those with children with conduct disorders, this includes:

- Assessing and referring appropriately to a specialist;
- Treating comorbid substance misuse if appropriate;
- Explaining implications of conduct disorder without treatment;
- Advising parents about clear communication;
- Advising parents about structured activities;
- Encourage involvement in supervised peer activities;
- Help establish a daily routine;
- Advising about positive reinforcement; and
- Consider pharmacology.

Identification of conduct disorder in schools is also possible; in one research project a teacher screening programme was able to identify children who later used mental health services³⁶ and thus enabled early intervention to support the child with their behaviour problems.

³⁶ Nix, R.L., Pinderhughes, E.E., Bierman, K.L., Maples, J.J., & the Conduct Problems Prevention Research Group, *Decoupling the relation between risk factors for conduct problems and the receipt of intervention services: Participation across multiple components of a prevention program*, *Journal of Community Psychology*, vol. 36 (2005), pp. 307-325

Family Intervention

Family intervention is an important element of treatment of conduct disorder, in particular for younger children. There are two types:

1. Parent education about the cycle of events that leads to problem conduct behaviours; and
2. Parent management training to improve parenting skills and to manage child behaviour effectively without the use of physical punishment³⁷.

Research into a UK based parenting programme within Sure Start Centres titled '*Incredible Years basic parenting programme*' showed significant improvement in problem behaviour in children³⁸. The programme is a group based and runs for 12 weeks with parents of 36 to 59 month olds children at risk of conduct disorder.

Evidence suggests that specific parent education and training programmes to manage early signs of conduct disorder can have good medium to long term effects at relatively low cost³⁹. Family intervention projects in the UK include Family Nurse Partnerships, and parenting programmes such as Triple P and Incredible Years, aimed at the families of children aged 3–11 who are showing early signs of behavioural problems. Scott (2008) concluded that parent training is emerging as the most effective intervention for conduct disorder⁴⁰.

Recent UK based evidence has concluded that parenting programmes reduce the chance that conduct disorder persists into adulthood are cost saving to the public sector within 5-8 years⁴¹, this is based on analysis limited to reduced expenditure related to the prevention of crime only. Recent research therefore concludes that investing in high quality, evidence based parenting programmes could bring significant cost savings to the public sector as well as benefits to society. Additionally research by Woolfenden, Williams and Peat showed that family and parenting interventions significantly reduced the time spent by juvenile delinquents in institutions....there was also a significant reduction in the risk of a juvenile delinquent being rearrested⁴². More recent UK research also supports these conclusions following a review of three programmes (Incredible Years, Triple P and Strengthening Families Strengthening Communities). It goes further to say "evidence based parenting programmes can be implemented successfully in a large scale in community settings"⁴³.

³⁷ Children's Mental Health Ontario, 2001: 14, also Harvard Medical School, 2011

³⁸ Hutchings, J., *et al*, 2007. Parenting intervention in Sure Start services for children at risk of developing conduct disorder: pragmatic randomised controlled trial. *British Medical Journal*

³⁹ Scott, Spender, Doolan, Jacobs and Aspland, 2001. Multicentre controlled trial of parenting groups for child antisocial behaviour in clinical practice. *British Medical Journal* 323:194-197

⁴⁰ Scott, S., 2008. An update on interventions for conduct disorder. *Advances in Psychiatric Treatment*, vol 14, pp 61-70

⁴¹ Boin *et al*. 2011. Costs and longer-term savings of parenting programmes for the prevention of persistent conduct disorder: a modelling study. *BMC Public Health*, vol 11

⁴² Woolfended, S., Williams, K., and Peat, J., 2002. Family and parenting interventions for conduct disorder and delinquency: a meta-analysis of randomised controlled trials. *Archives of Disease in Childhood*, vol 86, pp 251-256

⁴³ Lindsay, G., Strand, S., and Davis, H., 2011. A comparison of the effectiveness of three parenting programmes in improving parenting skills, parent mental-well-being and children's behaviour when implemented in a large scale in community settings in 18 English local authorities: the parenting early intervention pathfinder. *British Medical Association Public Health*, vol 11: 962

For children aged between three and 12 parent management training (delivered in individual parent-child sessions or in a parenting group) has been shown to be effective and studies into behavioural parent training suggest that there's a short term reduction in anti-social behaviour with enduring effects in some studies of up to six years.⁴⁴

For children who are 12 years or younger NICE recommends group-based parent-training/education programmes in the management of children with conduct disorders. Individual-based programmes are only recommended where the family's needs are too complex for a group-based programme⁴⁵. NICE guidance states that all group-based and individual programmes should be based on the principles of social learning theory, ways of improving family relationships, focus on parents identifying their own goals, include role plays and use any instruction manuals that are available for the programme. The guidance also states that enough sessions should be offered (between 8 and 12) and that they should be delivered by suitably trained and supervised.

Functional Family Therapy is an intervention for teenagers with serious anti-social behaviour with an established evidence base with reoffending rates 20-30% lower than in control groups⁴⁶. This involves the worker helping families understand that change is possible and that accessing support is positive to dispel any negative perceptions. Re-framing is a central tool to help young people with behaviour change and then working to embed that change. The four phases are: 1) securing engagement; 2) encouraging motivation; 3) seeking behaviour change; and 4) generalising that change to other similar situations.

Whilst functional family therapy is supported by research, there a number of factors that have been found to influence non-compliance; holding group sessions at convenient times and at comfortable locations are two⁴⁷. Providing sibling care, transport and other incentives can also motivate participation. It is also thought that a staff attitude of 'never give up' increases participation levels as well as the therapist understanding the parental viewpoint.

Recommended family intervention includes:

- Parent support that builds up parental strengths;
- Parent training on behaviour management;
- Family therapy and
- Treatment of substance misuse and other problems of parents and/or other family members.

Whilst family based interventions, in particular, parent training, are seen as an important first step treatment, the evidence does suggest that it needs to be targeted appropriately to get the best outcomes. The Centre for Mental Health has noted that programmes focused on children with the most severe problems produce the highest benefits for parents and children and have the highest returns.⁴⁸

⁴⁴ Scott, S., 2008. An update on interventions for conduct disorder. *Advances in Psychiatric Treatment*, vol 14, pp 61-70

⁴⁵ NICE, 2006, Parent-training/education programmes in the management of children with conduct disorders Technology appraisals, TA102

⁴⁶ Scott, S., 2008. An update on interventions for conduct disorder. *Advances in Psychiatric Treatment*, vol 14, pp 61-70

⁴⁷ Nix et al, 2005

⁴⁸ Brown, E., Khan, L. and Parsonage, M., 2012, *Delivering effective parenting programmes to transform lives*

Cognitive Behavioural Therapy

Work to pull together the effective interventions for children and young people with conduct disorder in Canada states that the main evidence-based individual therapy with conduct disorder youth is cognitive behavioural therapy⁴⁹. This work, as with work by Scott (2008)⁵⁰, highlights Problem Solving Skills Training (PSST) in particular to help control antisocial behaviours and strengthen pro-social functioning. Two programmes have been found to be effective for children. PSST and PSST (in vivo) for children over seven showed a decrease in deviant behaviour. PSST (in vivo) involved real life practice and a parent training element – this increased the outcomes achieved. Evaluations of Coping Power for those aged eight and over showed a reduction in aggression, substance misuse and improved social competence. However, the long term efficacy of such interventions has not been established. As Joughin (2006) reports on two meta-analysis articles and concludes:

“Overall, child-based CBT interventions have been found to have a positive, but modest, effect in decreasing antisocial behaviour. The most promising effects were found by a recent meta-analysis of forty published and unpublished studies, measuring CBT’s effect on anger and anger-related outcomes. The children were aged between 7 and 18 (average age 12.5). A smaller, but still positive, effect was found by an older meta-analysis of thirty studies. The children in this review were slightly younger (average age 11.48) and the authors suggest that CBT may have a larger effect with older school-aged children and adolescents than with younger children. This review looked at the effect on antisocial behaviour, and therefore included a wider range of outcomes than the review focusing on anger-related outcomes only.”⁵¹

School based interventions

The next section details the school based programmes. School programmes are very important given most conduct problems will present there first. Such programmes can be effective in addressing conduct problems particularly if this is where behaviour problems are arising. The types of support that can be effective in schools are:

- Anger management;
- Conflict resolution;
- Social problem solving; and
- Social skill training.⁵²

American research by Webster-Stratton *et al.* (2008) investigates how training for teachers can prevent conduct problems and improve school readiness. Results show that the teachers involved in the intervention used more positive classroom management strategies and the students showed more social competence and ability to manage their emotions. The programme for teachers included delivering a specific curriculum (Dinosaur School), classroom management techniques and strategies to promote emotional literacy and

⁴⁹ Children’s Mental Health Ontario, 2001. Evidence based practices for conduct disorder in children and adolescents

⁵⁰ Scott, S., 2008. An update on interventions for conduct disorder. *Advances in Psychiatric Treatment*, vol 14, pp 61-70

⁵¹ Joughin, C., 2006, Cognitive behaviour therapy can be effective in managing behavioural problems and conduct disorder in pre-adolescence. *What Works for Children group: Evidence Nugget*

⁵² Children’s Mental Health Ontario, 2001. Evidence based practices for conduct disorder in children and adolescents

promote pro-social behaviours as well as ways to encourage parents to be involved in their child's education and behaviour management.⁵³

However, there is little evidence to support behaviour change once the programmes have ended and advice to teachers and school staff may be required.

Scott, (2008) highlights the following four common targets of classroom techniques for children aged 3 – 12 to promote positive behaviour, these are:

- Promoting positive behaviours such as compliance and following established class room rules and procedures;
- Preventing problem behaviours such as compliance such as talking at inappropriate times and fighting;
- Teaching social and emotional skills such as conflict resolution and problem-solving; and
- Preventing the escalation of angry behaviour and acting out.⁵⁴

Implementing these targets could include setting class rules which are negotiated and agreed with the class and subsequently sent to parents to provide a systematic and consistent response when either following or not following the rules.

Research in the UK evaluating the Targeted Mental Health in Schools (TaMHS) programme found some positive results in terms of behaviour difficulties in primary schools as self-reported by pupils and teachers. The research found that there was no decrease in behavioural difficulties as reported by pupils in secondary schools. The evaluation found that the following factors were associated with change in mental health over time were school reports of:

- Giving information to pupils in secondary schools were associated with improvements in outcomes for children with behavioural problems;
- Use of Common Assessment Framework (CAF) were associated with improvement over time in secondary school children's behavioural problems.
- Good links with Children and Adults Mental Health Service were associated with improvement over time in secondary school children's behavioural problems.⁵⁵

The evaluation also found through using a Random Controlled Trial that:

“The most strongly endorsed category in both primary and secondary schools (apart from promotion of social and emotional development which all schools had to be doing as part of selection criteria for TaMHS implementation) was work on behaviour management in relation to behavioural difficulties.” (p.96)

⁵³ Webster-Stratton et al, 2008, “Preventing conduct problems and improving school readiness: evaluation of the Incredible Years and Child Training Programs in high risk schools” in The Journal of child psychology and psychiatry, vol 49, no 5, pp 471-488

⁵⁴ Scott, S., 2008. An update on interventions for conduct disorder. Advances in Psychiatric Treatment, vol 14, pp 61-70

⁵⁵ UCL and Anna Freud Centre, 2011, Me and My School: Findings from the National Evaluation of Targeted Mental Health in Schools 2008-2011, available at: <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RR177#downloadableparts>

The study made some recommendations for interventions in schools, including:

- Assess for developmental disorders;
- Place the child in an appropriate class;
- Educate teachers about the effective behaviour management for conduct disorder;
- Promote pro-social interactions with peers;
- Promote the use of CAF in secondary schools for young people with behaviour problems as a way of improving multi agency intervention; and
- Develop materials and processes for providing information for children and young people to help them access appropriate sources of support (advice lines, leaflets, texting services, and internet based information).

Peer Intervention

As children grow into young adults the influence of teachers and families may diminish with peers becoming arguably a more influential resource, for this reason, “*to avoid conduct disordered behaviour, intervention may be necessary to remove... (a young person)...from an antisocial group and help them to develop a new peer group*” (p.16).⁵⁶ Additionally supporting young people to promote pro-social interactions with peers are also recommended interventions for young people with conduct disorder.

Pharmacology

Research from Canada concludes that pharmacology is not sufficient to treat conduct disorder⁵⁷. However, it is found to be appropriate where the child or young person have a co-morbid disorder for example ADHD. Pharmacotherapy may help specific symptoms of the conduct disorder, stimulants, antidepressants; anticonvulsants are all types of medication that are used to support those with different symptoms.⁵⁸

Harsh and outdoor interventions

Evidence about the effectiveness of boot camp type interventions is mixed, with some research concluding that they are ineffective and others that they have a small overall effect.⁵⁹

Multi type and system interventions

As with other mental health problems wider determinants may affect the impact of any support, as such there are a number of issues that should be addressed before treatment should begin (where possible). The wider determinants include:

- Appropriate housing;
- Adequate resources to meet basic needs;
- Parents with psychiatric to substance misuse problem are accessing treatment;
- Safe home; and
- Appropriate parenting and supervision.

Research and practice consensus indicates that successful treatment must address multiple domains in a coordinated manner over a period of time. Outpatient treatment of conduct disorder usually involves the child/youth, family, school and peer group. Some milder forms

⁵⁶ Children’s Mental Health Ontario, 2001. Evidence based practices for conduct disorder in children and adolescents

⁵⁷ Ibid

⁵⁸ Searlight. H. et al., 2001, “Conduct disorder: diagnosis and treatment in primary care” in American Family Physician, vol 63, no 8

⁵⁹ Scott, S., 2008. An update on interventions for conduct disorder. Advances in Psychiatric Treatment, vol 14, pp 61-70

of conduct disorder however require minor intervention, usually training for the child (social skills and problem solving) and training for the parents (behaviour management, parenting skills) and consultation to schools. Moderate and severe conduct disorder often involves comorbid disorders that require treatment⁶⁰. Nix *et al.* (2006)⁶¹ concludes that an indicated prevention program for young people with early signs of conduct disorder made up of therapeutic groups, school based interventions and home visits was able to reach children and parents that may not have participated in services otherwise.

Multi-systematic therapy is the most developed multiple-component interventions⁶² for teenagers, however effectiveness has been shown to be variable. The Harvard Medical School report that randomised control trials have concluded that the therapy is effective at “reducing delinquent behaviour and drug use and preventing incarceration or hospitalisation”.⁶³ Scott (2008)⁶⁴ however reports that effectiveness has been variable depending on how close the therapists were to the programmes developers. There are nine principles to this type of therapy:

1. Assess to understand the context to the young person’s mental health problems (no assumption of intrinsic deficit);
2. Emphasise the strengths and the positives and work on those;
3. Promote responsible behaviour;
4. Interventions to focus on action with specific and measurable goals;
5. Interventions target sequences of behaviour in different systems that maintain problems;
6. Interventions match development stage;
7. Interventions require family members involvement;
8. Evaluate interventions from different perspectives; and
9. Empower parents to address their children’s needs across a number of different contexts

It involves considering and working to change a number of “systems” that affect a child or young person’s behaviour (the child/young person themselves, family, school, peers, etc.). This type of treatment can include a variety of the different approaches discussed above (cognitive therapy, parent training, and family therapy) – this is based on the assumption that antisocial behaviour has different causes.

Recommendations by NICE

NICE guidelines recently published (March 2013)⁶⁵ spell out a list of core conduct disorder symptoms to help with recognition/assessment as well as detailing interventions found to be helpful across the age groups. These include: parent training programmes, foster carer/guardian training programmes, child-focussed programmes and intensive multimodal interventions involving 3-4 contacts with the young person/family per week (for example, Multisystemic Therapy) .

⁶⁰ Children’s Mental Health Ontario, 2001. Evidence based practices for conduct disorder in children and adolescents

⁶¹ Nix *et al.* (2006)

⁶² Scott, S., 2008. An update on interventions for conduct disorder. *Advances in Psychiatric Treatment*, vol 14, pp 61-70

⁶³ Harvard Medical School, 2011. Options for managing conduct disorder. *Harvard Mental Health Letter*, vol 27, no 9

⁶⁴ Scott, S., 2008. An update on interventions for conduct disorder. *Advances in Psychiatric Treatment*, vol 14, pp 61-70

⁶⁵ NICE. March 2013. Antisocial behaviour and conduct disorders in children and young people: recognition, intervention and management. Accessed at: <http://publications.nice.org.uk/antisocial-behaviour-and-conduct-disorders-in-children-and-young-people-recognition-intervention-cg158/recommendations>

Recommendations for the components of a comprehensive assessment given are:

1. When providing information about local care pathways for children and young people with a conduct disorder and their parents and carers: 1) take into account the person's knowledge and understanding of conduct disorders and their care and treatment; and ensure that such information is appropriate to the communities using the pathway.
2. The use of Risperidone for the short-term management of severely aggressive behaviour in young people with a conduct disorder who have problems with explosive anger and severe emotional dysregulation and who have not responded to psychosocial interventions is recommended. However, NICE advise that young people and their parents or carers should be given age-appropriate information and a discuss should be had around the likely benefits and possible side effects of Risperidone. Also that Risperidone should be started by an appropriately qualified healthcare professional with expertise in conduct disorders and should be evaluated carefully.
3. To improve access to services health and social care professionals, managers and commissioners need to collaborate with colleagues in educational settings to produce local care pathways that promote access. They specify that services need to be offered in a variety of settings, using an assessment of local needs as a basis for the structure and distribution of services.
4. Support access to services and increase the uptake of interventions by providing services for children and young people with a conduct disorder and their parents and carers, in a variety of settings.
5. Health and social care professionals working with children and young people who present with behaviour suggestive of a conduct disorder, or who have a conduct disorder, should be trained and competent to work with children and young people of all levels of learning ability, cognitive capacity, emotional maturity and development.

The OFSTED report 'Edging away from care – how services successfully prevent young people entering care (2011)⁶⁶ addressed young people and families sharing many features with those with conduct problems. The report emphasise the need for:

- Perseverance with families who often didn't want to engage with them
- The need to respond quickly, often outside working hours and to work intensively with families
- Clarity of model so that young people and families understood the overall direction, plan and timescales of the intervention
- Listening to the views of the young person and family and building upon strengths and
- The need for multi-agency working.

3. What does the evidence say are effective approaches to early intervention in psychosis?

Adolescence and emerging adulthood are a high-risk time for developing mental disorders; in England 7,500 young people develop an emerging psychosis each year. The early phase of psychosis is a critical period affecting long-term outcomes. Failure to intervene early often

⁶⁶ Ofsted (October 2011). Edging away from care – how services successfully prevent young people entering care

has significant personal costs in terms of an individual having reduced capacity to reach their social, emotional and vocational potential, as well as wider social and economic costs.⁶⁷

The importance of improving youth mental health is advocated in the current mental health strategy, *No Health without Mental Health* (2011)⁶⁸ which embraces a shift in focus of services towards promotion of mental health, prevention of mental illness and early identification and intervention across the life course. Key priorities running through the strategy include prioritising early intervention (EI) across all age groups, tackling health inequalities, and supporting people who experience mental ill health to recover meaningful lives. There are several outcomes that have particular relevance to improving the health and life chances of people with psychosis, which include employment, housing and physical health and mortality, as well as promoting personalisation approaches. The strategy is also clear that these outcomes need to be improved while making efficiency savings.

Early detection

Early intervention can mean improving outcomes in established cases of psychosis by facilitating and consolidating recovery, identifying untreated cases in the community, or preventing the emergence of psychosis through pre-psychotic interventions⁶⁹. There were two elements that were identified as essential in order to achieve this; the first is to be able to accurately identify those at risk of developing the illness and the second is the need for effective treatments in slowing or preventing progression to illness⁷⁰.

Critical period

Studies of first-episode psychosis show that the average time between onset of symptoms and first effective treatment is often one year or more⁷¹. There are two major clinical reasons for ensuring this long duration of untreated psychosis is undesirable. The first is the known association between a long duration of untreated psychosis and a poor outcome in the short term^{72 73}. Personal, social and societal consequences are well known to sufferers and their families and provide the major justification for early intervention. The other key reason for early intervention is the notion that the first 3 years of psychosis constitutes a critical period during which repeated relapses occur, a pattern of repeated admissions is established, long-term treatment resistant symptoms emerge and major personal, social and occupational disabilities accumulate⁷⁴. The level of disability and impairments accrued in the first 2 years of the illness may also impact on the long-term recovery process, making a strong case for effective interventions during this period⁷⁵. This concept of the early phase of psychosis as a critical period for addressing drivers of future disability and premature death has underpinned the emergence of a strong bio-psycho-social model of care.

⁶⁷ Mental Health Network NHS Confederation May 2011 Briefing: Early intervention in psychosis services, Issue 219.

⁶⁸ No health without mental health strategy 2011

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123766

⁶⁹ Swaran, P. Singh & Helen L. Fisher (2005) Early interventions in psychosis: obstacles and opportunities. *Advances in Psychiatric Treatment*. Vol 11, 71-78.

⁷⁰ Killackey, E. & Yung, A. R. Effectiveness of early intervention in psychosis. *Psychiatry* 2007, 20:121-125.

⁷¹ McGlashan, T.H. (1987) Recovery style from mental illness and long-term outcome. *Journal of Nervous and Mental Disease*, 175, 681-685.

⁷² Loebel, A. D., et al (1991) Duration of psychosis and outcome in first episode schizophrenia. *American Journal of Psychiatry*. 149, 1183-1188.

⁷³ Norman, R. M. G & Malla, A. K. (2001) Duration of untreated psychosis: a critical examination of the concept and its importance. *Psychological Medicine*, 31, 381-400.

⁷⁴ Birchwood, M., et al (1998) Early intervention in psychosis. The critical period hypothesis. *British Journal of Psychiatry*. 172 (suppl. 33), 53-59.

⁷⁵ Mason, P., et al (1995) Characteristics of outcomes in schizophrenia at 13 year. *British Journal of Psychiatry*. 167, 596-603

Evidence base for early intervention in psychosis (EIP)

Harrison *et al.* (2001)⁷⁶ showed how the outcome at 2-3 years strongly predicts outcome twenty years later. Delay in first treatment is linked strongly with poor outcomes. Short term improved outcomes in comparison to standard care have been widely reported in symptoms reductions, vocational and social functioning, reduced inpatient care and treatment dropout⁷⁷
78 79

A systematic appraisal of the evidence for EIP was undertaken for the Cochrane Database found strong evidence for the link between a long duration of untreated psychosis (DUP) and poor outcomes⁸⁰. In addition to this, the Danish OPUS study⁸¹, a randomised controlled trial, compared early intervention with standard treatment. The study convincingly demonstrated a beneficial effect after two years. The intervention group had a significantly lower level of psychotic and negative symptoms, fewer in-patient days, better treatment adherence and higher level of user satisfaction.

Research conducted by the Lambeth Early Onset Service (LEO) clearly indicated that EIP delivers better outcomes than standard Community Mental Health Teams (CMHT) care. EIP clients were more often in regular contact with the clinical team and were more than likely to attend appointments; they were more likely to have been offered psychosocial interventions and to be in recovery. They also had fewer admissions and better social and vocational functioning.⁸²

The first UK study to specifically analyse the economic impact of EIP modelled the costs associated with early Intervention and standard care over a one-year and a three-year period. They found that the participants in the specialised programme group had more contact with clinical and supportive services. They also had less need for in-patient services and their in-patient costs were only two-thirds of the costs of the standard care group^{83 84}.

Evidence-based considerations for effective EIP teams⁸⁵

The IRIS Guidelines (2012) made the following recommendations:

- Orientated particularly to working with young people and their families, a therapeutic culture of respect and recovery needs to be nurtured, with the effects of stigma being appreciated and actively countered.

⁷⁶ Harrison G, Hopper K, Craig T, et al (2001). Recovery from psychotic illness: a 15 and 25-year international follow-up stud. *British Journal of Psychiatry*, 17, 506-517

⁷⁷ Craig T. K. J., et al. (2004) The Lambeth Early Onset (LEO) Team: randomized controlled trial of the effectiveness of specialised care for early psychosis. *BMJ* 329: 1067.

⁷⁸ Dodgson G., et al (2008) Early intervention in psychosis service and psychiatric admissions. *Psychiatric Bulletin*, 32, 413-416.

⁷⁹ Peterson L., et al (2005) A Randomised multicentre trial of integrated versus standard treatment for patients with first episode psychotic illness. *BMJ*, 331, 602.

⁸⁰ Marshall M., et al (2005) Association between duration of untreated psychosis and outcome in cohorts of first episode patients. *Arch gen Psychiatry*; 62: 975-83.

⁸¹ Peterson L., et al (2005) A Randomised multicentre trial of integrated versus standard treatment for patients with first episode psychotic illness. *BMJ*, 331, 602.

⁸² Craig T. K. J., et al. (2004) The Lambeth Early Onset (LEO) Team: randomized controlled trial of the effectiveness of specialised care for early psychosis. *BMJ* 329: 1067.

⁸³ McCrone P., et al (2010) Cost-effectiveness of an early intervention service for people with psychosis. *Br j Psychiatry* 196: 377-82.

⁸⁴ McCrone P., et al (2009) Economic impact of services for first-episode psychosis: a decision model approach. *Early Intervention in Psychiatry*, 3, 266-273.

⁸⁵ IRIS Guidelines Update September 2012 – revision of the original 1998 IRIS guidelines

- Dedicated leadership is vital to service culture, ensuring that EIP services are led in accordance with research-based best practice and for the continuous improvement of the service, workforce development and clinical governance.
- Team approach, the ability to share information and to work effectively within the multi-disciplinary team is essential. This involves a willingness to share roles within the team to meet the needs of individual clients.
- Multi-disciplinary team skill mix, to provide youth working, psychosocial and occupational skills, family work, service user posts. The skills for working with children and people with a dual diagnosis are essential and support workers are vital to maintaining high levels of community support. Recovered EIP service users can help enormously in such roles.
- Assertive community treatment that is flexibly applied according to need. A team-based approach which will vary in intensity depending on the individual's needs and their progress. Ensure young people feel meaningfully engaged to receive evidence-based interventions, promote their recovery and reduce risk.
- Low caseloads – a team caseload should equate to no more than an average of 12-15 cases per key worker.

Evidence-based principles of care and treatment⁸⁶

The IRIS Guidelines (2012) also made the following recommendations in respect to principles of care and treatment:

- Age-appropriate services and youth friendly approach (age, culture and gender sensitive)
- Engagement alongside expert management, including:
 - Meaningful and sustained engagement based on assertive outreach principles.
 - Promote early detection and referral by community agencies.
 - Reduce treatment delay.
 - Tolerate diagnostic uncertainty whilst addressing key problems by managing symptoms rather than the diagnosis.
 - Optimise initial service experience – home treat/youth friendly inpatient care.
- Family oriented – supporting the family as part of the care team
- Maximise recovery and prevent relapse during critical period, including:
 - Provide age and phase biological, psychological and social interventions.
 - Emphasis on normal social roles and service user's development needs, particularly in terms of accessing education and achieving employment.
 - Address co-morbid substance misuse and treatment resistance early.
 - Screen for and modify physical health risks – promote wellbeing.

What constitutes early intervention?

To answer the above question, the evidence is split into three parts:

- 1) Prodromal interventions
- 2) Early detection in the community
- 3) Facilitating recovery in first-episode psychosis

⁸⁶ IRIS Guidelines Update September 2012 – revision of the original 1998 IRIS guidelines

1) *Prodromal interventions*

Preventing psychosis by intervening in the prodrome remains ethically contentious and clinically challenging, given the non-specificity of prodromal symptoms and their low predictive power in identifying individuals who will make a transition to psychosis⁸⁷. However, some of the potential benefits of pre-psychotic and prodromal interventions include: disability accumulates in the prodromal state, therefore creating an avenue for help is warranted; rapid intervention can be offered for those who progress to psychosis; comorbidity such as substance misuse can be managed and engagement and trust are more likely to be established. Some potential pitfalls include: there are no clear markers for identifying true positive cases which can lead to demoralisation and unnecessary treatment in false positive cases.

Greater evidence is needed on the efficacy of interventions at this stage – for now, early intervention services should concentrate primarily on treating cases of established psychosis and prodromal cases should be monitored and treated symptomatically until further evidence of effective treatment emerges.

2) *Early detection in the community*

A consistent finding is that mean duration of untreated psychosis is long between 1-2 years⁸⁸. Untreated psychosis is likely a combination of patient delay, diagnostic delay and service delay. Several methods have been recommended for reducing this treatment delay, including structural changes to remove barriers to care and facilitate access to service, developing outreach programmes for community detection and the use of media for educating both professional and the general public⁸⁹. Some early detection strategies include: ant stigma and community education campaigns; educating GPs and other key agencies such as educational authorities, youth services and young offender programmes; well-defined care pathways and referrals and service promotion. However before delivering such approaches it is important to understand there is more to early intervention than intervening early, it also requires effective strategies for intervention are in place.

3) *Facilitating recovery in first-episode psychosis*

Evidence is accumulating that effective and assertive early intervention in first-episode psychosis improves short-term outcomes.

Phase-specific strategies for facilitating recovery in established psychosis have been identified and include:

Acute Phase

- Multidisciplinary assessment of mental state, risk, support and needs.
- Allocation of care coordinator.
- Embracing diagnostic uncertainty by focusing on broad psychosis rather than narrow schizophrenia.

⁸⁷ Harvey, P. D. (2003) Chickens and eggs: carts and horses: an outsider's perspective on the study of the early stages and potential prevention of psychosis and schizophrenia. *Schizophrenia Bulletin*, 29, 845-849

⁸⁸ Norman, R. M. G & Malla, A. K. (2001) Duration of untreated psychosis: a critical examination of the concept and its importance. *Psychological Medicine*, 31, 381-400.

⁸⁹ Malla, A. K. & Norman, R. M. G. (2002) Early intervention in schizophrenia and related disorders: advantages and pitfalls. *Current Opinion in Psychiatry*, 15, 17-23.

- Ensuring a benign therapeutic start by offering non-coercive treatment in low stigma settings, with in-patient treatment if needed.
- Use of low-dose atypical antipsychotics.
- Ensuring therapeutic engagement.

Recovery Phase

- Ensuring medication adherence.
- Individual therapy, including cognitive behavioural therapy.
- Assessment and management of comorbidity (especially depression and substance misuse).
- Monitoring of mood for early identification of hopelessness, pessimism or suicidal ideation.
- Psychoeducation for carers and behavioural family intervention.
- Engaging carers as therapeutic allies.
- Vocational assessment.
- Regular, structured and documented multidisciplinary review of care plan with user input into needs assessment and the plan itself.

Consolidating recovery and discharge planning

- Relapse-prevention strategies.
- Early warning signs drill.
- Recovery groups.
- Vocational rehabilitation.
- Enhancing independence by addressing social outcome, leisure activities and housing.

The most well-known and best-evaluated service is the Early Psychosis Prevention and Intervention Centre (EPPIC), in Melbourne, Australia. Patients of this programme have been reported to experience better outcome with regard to overall quality of life and social functioning, have a lower average length of hospital stay and receive lower mean doses of neuroleptics than non-EPPIC patients⁹⁰. This service has also been shown to be more cost effective than generic services as there is improved community care and reduced in-patient cost⁹¹. Other early intervention services in have demonstrated favourable results of early intervention. For example, patients who received treatment from stand-alone services in Denmark and Norway demonstrated greater improvements in medication adherence and vocational outcomes as well as experiencing marked reductions in duration of untreated psychosis compared with those treated by generic services^{92 93}.

⁹⁰ McGorry, P. D. & Edwards, J. O. (1998) The feasibility and effectiveness of early intervention in psychotic disorders: the Australian experience. *International Clinical Psychopharmacology*, 13 (suppl. 1) S47-S52.

⁹¹ Mihalopoulos, C., et al (1999) Is phase-specific, community-oriented treatment of early psychosis an economically viable method of improving outcome? *Acta Psychiatrica Scandinavica*, 100, 47-55.

⁹² Johannessen, J. O. et al (2000) Early intervention in psychosis: the TIPS project, a multi-centre study in Scandinavia. In *Psychosis: Psychological Approaches and their effectiveness* pp210-234. London: Gaskell.

⁹³ Jorgensen, P., et al (2000) Early detection and assertive community treatment of young psychotics: the OPUS Study. Rationale and design of trial. *Social Psychiatry and Psychiatric Epidemiology*, 35, 283-287.

Service models

There are three basic models whereby early intervention can be provided.⁹⁴

1) Enhancing existing community mental health teams

This model involves generic services adopting the principles of early intervention for the treatment of patients with first-episode psychosis either through education of the whole team or by employing a specialist worker. This can be an inexpensive option however it does not necessarily ensure specific and optimal treatment for this client group.

2) 'Hub and spoke' model

This model consists of a central specialist service (the 'hub') that supports existing generic teams by providing specialist input (the 'spokes') for individual patients. This requires fewer resources than a stand-alone team and could be a useful stepping stone for fledgling services. However, there is potential for uncertainty and confusion regarding each service's responsibility for these patients, together with a disruption of continuity of care.

3) Stand-alone early intervention service

This is advocated as the gold standard for the UK (Department of Health 2001: The Mental Health Policy Implementation Guide). This ensures provision of a comprehensive early intervention package delivered by dedicated and trained staff. However it is resource intensive, may result in the loss of a single point of entry into mental health services and has implications for continuity of care when its time-limited intervention has expired. Figure 3 shows the components of a well-funded stand-alone early intervention service.

Figure 3. Components of a well-funded stand-alone early intervention service

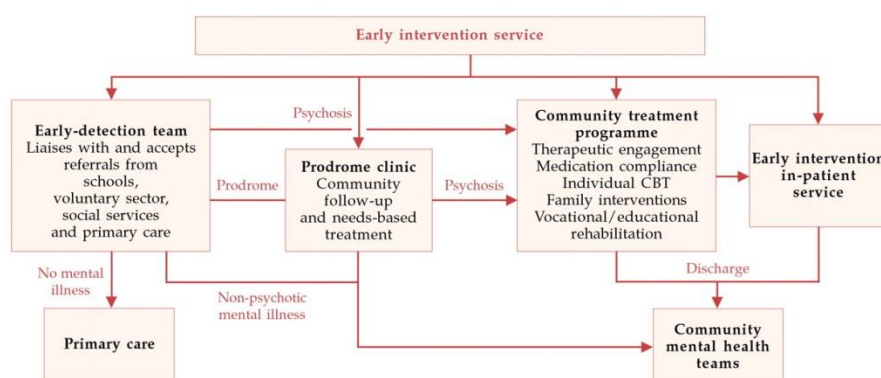


Fig. 1 A model for an effective early intervention service. Adapted from Singh & Fisher (2004).

Source: Singh, S. P. & Fisher, H. (2004) Early intervention services. *Psychiatry*, 3, 17-21.

Lambeth Early Onset Service (LEO) is an example of an early intervention service in South London⁹⁵. This service started as a research trial comparing specialist assertive community treatment of early psychosis with standard care from existing generic services. It is a secondary service for all patients with first-episode psychosis (aged 16-35 years) in the Lambeth. It was found that there was a beneficial effect of the early intervention on readmissions and dropouts. Further analysis of this study showed that the intervention group

⁹⁴ Singh, S. P. & Fisher, H. (2004) Early intervention services. *Psychiatry*, 3, 17-21.

⁹⁵ Craig T. K., et al (2004) The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis, *BMJ*; 329: 1067.

were more compliant with medication, spent more time engaged in educational or vocational pursuits, and established or re-established relationships better than the control group⁹⁶. The LEO trial shows that early intervention can achieve gains in both clinical and functional aspects of early psychosis.

Length of treatment

The first 5 years post onset of psychosis has identified as being a critical period⁹⁷ and yet many early interventions programmes provide only 18 months or at best 3 years. Many outcome studies examine 1-year outcomes⁹⁸; the high rate of relapse in young people with psychosis has led to suggestions that a longer continuity of care within the first episode programmes is warranted⁹⁹. The length of treatment required in optimal early psychosis services warrants further investigation.

Guidance for service planners & commissioners

Psychosis is one of the most serious conditions that can affect a young person:

- Suicide – 10% lifetime risk; 66% within first 5 years
- 88% end up unemployed – can lead to social exclusion
- Costs are out of proportion to the relatively low prevalence of psychosis
- Estimated direct NHS cost of treating schizophrenia each year was £946m; 90% going towards inpatient care¹⁰⁰

Early intervention approaches can reduce service costs by about 35% mainly by lowering readmission rates despite higher costs of the actual EI team.¹⁰¹

Service planners can have confidence that early Intervention in psychosis service models address many of the efficiency challenges they currently face as there is a growing body of evidence that illustrates the clinical and cost effectiveness. It has been widely recognised across England that an at-risk service represents clear value for money, given the huge personal and social costs associated with the development of psychosis in a young person¹⁰², as well as the financial costs of psychosis to the NHS and social care.

Early Intervention in Psychosis (EIP) service provision is now established as a 'normal' part of the architecture of specialist services so that most young people with a first episode of psychosis in England can access a local EIP service. The robust research base has been translated into clinical practice, where a national 'upstream' service investment has been rewarded by better clinical outcomes, increased consumer satisfaction and reduction in downstream health utilisation¹⁰³. EIP services demonstrate an effective 'invest to save' approach which provides a key opportunity for cash-strapped service planners who want to provide high quality and innovative services.

⁹⁶ Garety P. A., et al (2006) Specialised care for early psychosis symptoms, social functioning and patient satisfaction: randomised controlled trial. *Br. J Psychiatry*; 188: 37-45.

⁹⁷ Birchwood M. & Fiorillo A. (2000) The critical period for early intervention. *Psychiatr Rehabil Skills. Special Issue: The British approach to psychiatric rehabilitation*; 4: 182-198.

⁹⁸ Addington J., et al (2003) Symptom outcome 1 year after admission to an early psychosis program. *Can J Psychiatry* 48; 204-207.

⁹⁹ Gleeson J. F., et al (2005) Early warning signs of relapse following a first episode of psychosis. *Schizophr Res*; 80:107-111.

¹⁰⁰ Patel & Knapp, 1998

¹⁰¹ McCrone & Kanpp – National EI seminar Dec 2007

¹⁰² McCrone P., et al (2010) Economic evaluation of early intervention (EI) services, phase IV report. PSSRU discussion paper 2745.

¹⁰³ IRIS (2010) Early intervention in psychosis – A briefing for service planners

4. What does the evidence say are effective approaches to improving the experience if people with mental health problems in primary care services?

It has been well documented that individuals with mental illness report high levels of mortality and higher physical health problems compared with the general population^{104 105 106}. People with mental health problems are more likely to be overweight, to report no leisure time physical activity and to receive certain preventative services at lower rates than recommended. A review by Felker *et al.* (1996) reported that people with mental illness experienced two times higher mortality rates than the general population¹⁰⁷. An Australian study reported that an individual with severe mental illness live between 25 and 30 years less than people in the general population and cardiovascular disease remains the most important cause of death and physical impairment among people with a mental illness¹⁰⁸.

A range of studies have shown that people with mental health problems report disproportionately high blood pressure, as well as bowel, breathing and heart problems compared with the general population¹⁰⁹. These findings support those of Lovett Doust (1980), who found that patients with schizophrenia were more likely to have abnormal variations in cardiac rate and were predisposed to obesity and type II diabetes¹¹⁰.

Individuals with mental illness have also high misdiagnosis, and high under diagnosis of major physical illnesses along with higher rates of unhealthy lifestyle behaviours (for example, high cigarette smoking)¹¹¹. It is important to recognise that attitudes towards and patterns of health care service utilisation among individuals with mental illness along with satisfaction with health care services are equally influential to this population's health outcome¹¹².

Characteristics of patients with mental illness have been identified as important factors in influencing the utilisation of health care services. Most notable were impaired communication skills, lack of skills and resources to use the health care system, dependency on care-givers, difficulty in following treatment plans, behaviour difficulties e.g. patients seen as chaotic and the denial of potential illness can delay these individuals from seeking needed health care or complying with treatment^{113 114}.

¹⁰⁴ Baxter, D. N. (1996) The mortality experiences of individuals on the Salford psychiatric case register. *British Journal of Psychiatry*, 168, 772-779.

¹⁰⁵ Coghlan, R., et al (2001) *Duty of Care: Physical illness in people with mental illness*. Perth: The University of Western Australia.

¹⁰⁶ Mortenson, P., Juel, K. (1993) Mortality and causes of death in first admitted schizophrenia patients. *British Journal of Psychiatry*, 163, 183-189.

¹⁰⁷ Felker, B. et al (1996) Mortality and medical comorbidity among psychiatric patients: A review. *Psychiatric Services*, 47, 1356-1363.

¹⁰⁸ Coghlan, R., et al (2001) *Duty of Care: Physical illness in people with mental illness*. Perth: The University of Western Australia.

¹⁰⁹ Berren, M. et al (1994) Series mental illness and mortality rates. *Hospital and Community Psychiatry*, 45, 604-605.

¹¹⁰ Lovett Doust, J. W. (1980) Sinus tachycardia and abnormal cardiac rate variation in schizophrenia. *Neuropsychobiology*, 6, 305-312.

¹¹¹ Coghlan, R., et al (2001) *Duty of Care: Physical illness in people with mental illness*. Perth: The University of Western Australia.

¹¹² Chou, K.-L. (2000) The utilisation of health care services by neurotic patients and their service needs. *International Journal of Social Psychiatry*, 136, 237-240.

¹¹³ Cradock-O'Leary, J., et al (2002) Use of general medical services by VA patients with psychiatric disorders. *Psychiatric Services*, 53, 874-878.

¹¹⁴ Beecroft, N., et al (2001) Physical health care for people with severe mental illness. The role of the general practitioner. *Journal of Mental Health*, 10, 53-61.

The attitude of medical professionals to people who are mentally ill may also be a factor in health care delivery for this population. A study by Kendrick *et al.* (1994)¹¹⁵ found that 63% of doctors thought that the long-term mentally ill posed communication problems between doctors and patients. Mentally ill patients were seen as disruptive, and 68% of doctors believed that they created more work for a practice.

Evidence also suggests a number of other factors which may prevent people from seeking help, including: 1) stigma; 2) family and friends; and 3) language barriers in disadvantaged groups¹¹⁶.

Many qualitative and quantitative studies have considered the impact of stigma^{117 118}, which can often influenced participants' attitudes towards seeking help^{119 120}. Studies have shown that stigma is particularly feared by ethnic minorities, who cited examples of significant social handicap, such as being '*unable to marry*'¹²¹, or being labelled as '*mad*'¹²² or '*crazy*'¹²³ by their society if they were known to need treatment¹²⁴.

Whilst many studies in fact show the value of family and friends, other studies report family and friends can either be helpful or unhelpful depending upon whether they recognized that the person is ill and believe that mental illnesses are treatable.^{125 126} In a number of qualitative studies, participants complained about family and friends' negative attitudes towards treatments and could delay, or prevent treatment.¹²⁷

*'I keep it to myself. I've given up saying to him [husband]. He thinks I'm just making a fuss about nothing'*¹²⁸.

*'I have thought about counselling, but... I would had to have done it against my husband's wishes.'*¹²⁹

¹¹⁵ Kendrick, T., *et al* (1994) Provision of care to general practice patients with long-term mental illness. *British Journal of General Practice*, 44, 301-305.

¹¹⁶ Eliminating Disparities in Mental Health: An Overview. NAMI 2006 Eliminating Disparities: Multicultural Strategic Summit

¹¹⁷ Cooper-Patrick, L., Powe, N.R., Jenckes, M.W., *et al.* (1997). Identification of patient attitudes and preferences regarding treatment of depression. *J Gen Intern Med*, 12, 431-438.

¹¹⁸ Grime, J., Pollock, K. (2003). Patients' ambivalence about taking antidepressants: a qualitative study. *Pharm j*, 271, 516-518.

¹¹⁹ Hussain, F., Cochrane, R. (2003). Living with depression: coping strategies used by South Asian women, living in the UK, suffering from depression. *Ment Health, Relig Cult*, 6, 25-44.

¹²⁰ Lavender, H. (2003). Attitudes towards depression and coping methods. MSc Thesis. University of London.

¹²¹ *Ibid*

¹²² Cinnirella, M., Loewenthal, K.M. (1999). Religious and ethnic group influences on beliefs about mental illness: a qualitative interview study. *Br J Med Psychol*, 72, 505-524.

¹²³ Egede, L.E. (2002). Beliefs and attitudes of African Americans with type 2 diabetes toward depression. *Diabetes Educ*, 28, 258-268.

¹²⁴ Templeton, L., Velleman, R., Persaud, A., *et al.* (2003). The experiences of postnatal depression in women from black and minority ethnic communities in Wiltshire, UK. *Ethn Health*, 8, 207-221.

¹²⁵ Templeton, L., Velleman, R., Persaud, A., *et al.* (2003). The experiences of postnatal depression in women from black and minority ethnic communities in Wiltshire, UK. *Ethn Health*, 8, 207-221.

¹²⁶ Karp, D.A., Tanarugsachock, V. (2000). Mental illness, caregiving, and emotion management. *Qual Health Res*, 10, 6-25.

¹²⁷ Schreiber, R., Stern, P.N., Wilson, C. (2000). Being strong: how black West-Indian Canadian women manage depression and its stigma. *J Nurs Scholarsh*, 32, 39-45.

¹²⁸ McIntosh, J. (1993). Postpartum depression: women's help-seeking behavior and perceptions of cause. *J Adv Nurs*, 18, 178-184.

¹²⁹ Rhea, M.H. (1989). Women's explanations for depression. PhD thesis. University of Utah.

Perspectives from the patients & health care professionals: Research and recommendations

Relatively little research has sought the views of people with serious mental illness on primary care services and even less research has incorporated the dual perspective of recipient and provider¹³⁰. The limited evidence base suggests that GPs are willing to take responsibility for physical health but do not perceive themselves as involved in the mental health or overall care of people with serious mental illness¹³¹. Some GPs also find it difficult to communicate with such patients. From the patients' perspectives it has been highlighted a perceived lack of information and explanation for patients about diagnosis and treatment, overuse of medication and delay in obtaining a diagnosis and barriers created by stigmatised attitudes^{132 133}. In the UK, the primary care clinical and policy context for people with serious mental health illness is changing as there is an increased emphasis on patient access and choice; and the care of such patients is included in the quality and outcomes framework of the new GP contract, which came into force in April 2004.

A qualitative across six primary care trusts in the West Midlands was carried out to explore the experience of providing and receiving primary care from the perspectives of primary care health professionals and patients with serious mental health¹³⁴. This study consisted of six patient groups¹³⁵, six health professional groups and six combined focus group. Many findings from this study support those from similar studies – particularly in relation barriers surrounding access to primary care services and continuity of care¹³⁶. Evidence of the pervasive effects of negative stereotypes of mental illness on health professional's attitudes and behaviours towards people with serious mental illness is also reinforced by this study.

This study¹⁷ adds to what is already known on this topic:

- Most patients with serious mental health illness view primary care as the cornerstone of their health care. Patients and health professionals agreed that the latter had a responsibility to continue prescribing drugs started in secondary care, monitor side effects, and tackle physical health issues. Both groups recognised that it was sometimes difficult to present with or diagnose physical complaints once a mental health disorder has been diagnosed. Most health professionals perceived the mental health care of people with serious mental illness as too specialised for routine primary care and felt they lacked sufficient skills and knowledge.
- Although GPs feel that lack of knowledge inhibits greater involvement in care, patients value continuity of care, listening skills, and willingness to learn more than specific knowledge about mental health.
- Most health professionals see serious mental health illness as a lifelong chronic disease, whereas patients prefer treatment to have an optimistic approach that recognises the possibility of recovery.

¹³⁰ Burns T., et al (2000) Attitudes of general practitioners and community mental health staff towards the locus of care for people with chronic psychotic disorders. *Primary Care Psychiatry*; 6:76-71.

¹³¹ Bindman J., et al (1997) Integration between primary and secondary services in the care of the severely mentally ill: patient's and general practitioner's view. *Br. J. Psychiatry* 171;169-74.

¹³² Bailey D. (1997) What is the way forward for a user-led approach to the delivery of mental health services in primary care? *J Mental Health*; 6; 101-5.

¹³³ Rogers A., et al (1993) *Experiencing psychiatry users' views of services*. London: Macmillan Press.

¹³⁴ Lester H. E., et al (2005) Patients' and health professionals' view on primary care for people with serious mental illness: focus group study *BMJ*; 1-6

¹³⁵ Participants were: Forty five patients with serious mental illness, 39 general practitioners (GPs), and eight practice nurses.

¹³⁶ Freeman G., et al. (2002) Promoting continuity of care for people with severe mental health illness whose needs span primary, secondary and social care. A report for the NCCSDO.

The importance attached to optimism in treatment, continuity of care, and listening skills compared with specific mental health knowledge may also encourage health professionals in primary care to play a greater role in the care of patients with serious mental illness.

A study¹³⁷ that examined the barriers faced by people with mental illness also explored patient perspectives on ways to improve the quality of primary health care:

- GPs must maintain up-to-date knowledge about the nature of mental illness: it is a long term illness that can improve over time and that can be managed with medication, therapy and other interventions. This can be done through training for primary care staff
- Address stigma, attitudes and behaviours towards mental illness in primary care.
- Develop good lines communication between patient and clinician which contributes towards a trusting and supportive relationship.
- Mental health support groups to share practical information, assess service satisfaction and community resources.
- Patients need to take a more active and committed role towards getting their health needs met and in assuring that coordination among clinicians occur.

The Liverpool Primary Care Trust was been awarded £2 million to investigate the issues surrounding the equity of access to high quality primary care mental health services for hard-to-reach groups, and how to increase that access¹³⁸.

This research was divided into three phases:

- Phase 1 (months 1 to 24) - Understanding the problems and generating potential solutions
- Phase 2 (months 19-48) - Testing potential solutions
- Phase 3 (months 43-60) - Putting what works into practice

A range of methodological approaches were used to gather data which included a review of the literature and a series of stakeholder consultations.

This study found the major barriers revolved around issues of stigma and discrimination, communication and inadequate information about mental health services. Other prominent themes included the problems of isolation and loneliness, and a diverse range of responses to distress.

The key messages and potential interventions that came out from this study included:

- *Attitude*: Being non-judgemental and anti-discriminatory and helping service users to feel better about themselves and their situation.
- *Communication*: Operating simple appointment systems and using a range of communication methods.
- *Inclusiveness*: Promoting user-led services, working with service users and earning the trust of local communities.
- *Information*: Publicising information on the role of the service and promoting knowledge and understanding of mental health issues.
- *Meaning*: Offering services that are meaningful to potential service users.

¹³⁷ O'Day B., et al (2005) Primary care experience of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*; 28:339-345.

¹³⁸ AMP (Improving Access to Mental Health in Primary Care) <http://www.liv.ac.uk/amp/index.htm>

- *Outreach*: Taking services to the people.

It also suggests that successful interventions should also:

- Focus on well-being
- Involve education/awareness raising
- Address physical and social health
- Promote cultural responsiveness
- Promote tailored care/therapeutic options
- Publicise services

5. What does the evidence say are the effective interventions to support patients with comorbid substance misuse problem?

Evidence demonstrates that individuals with a severe mental illness who also misuse substances (i.e., individuals with a dual diagnosis) have higher rates of poorer treatment outcomes, including relapse and hospital readmission¹³⁹. Furthermore, individuals who have a dual diagnosis experience more problematic outcomes across not only clinical domains but also experience severe psychosocial problems than those with either a substance abuse or a mental illness alone¹⁴⁰. This presents a significant challenge with respect to the identification, prevention and management of people with comorbid disorders. There is a compelling need for effective treatment strategies that embrace both substance misuse and mental health, taking useful and effective components of interventions from each and deploying these in an integrated manner.

Definition

The working definition used in this review was the one used by National Treatment Agency for Substance Misuse in their Misuse of drugs and other substances guidelines¹⁴¹.

Substance misuse is defined as intoxication by – or regular excessive consumption of and/or dependence on – psychoactive substances, leading to social, psychological, physical or legal problems. It includes problematic use of both legal and illegal drugs (including alcohol when used in combination with other substances).

Epidemiology

Epidemiological studies show that the use of substance misuse by people with a mental illness is much higher than rates of use among the general population. For example findings from a study by Tesson and Proudfoot reported comorbidity rates between 15-84%¹⁴². This figure was echoed by another study that clearly shows co-occurrence is the expectation rather than the exception¹⁴³. The problem is particularly amongst young people. Hides et al reported that in young people presenting for mental health support, the occurrence of comorbid substance misuse ranged between 11 and 71%, whereas for those presenting to

¹³⁹ Bellack A (2007). Issues in understanding and treating comorbidity in people with serious mental illness. *Clinical Psychology: Science and Practice*, 14:70-76.

¹⁴⁰ Minkoff, K. (2001). Best practices: Developing standards of care for individuals with cooccurring psychiatric and substance-use disorders. *Psychiatric Services*, 52, 597–599.

¹⁴¹ Accessed at: www.nice.org.uk/nicemedia/pdf/DrugMisuseFinal.ppt. Accessed July 2013.

¹⁴² Teeson M. & Proudfoot H. (Eds.) (2003). *Comorbid mental disorders and substance use disorders: epidemiology, prevention and treatment*. Commonwealth of Australia, Canberra: National Drug and Alcohol Research Centre.

¹⁴³ Buckley, P. (2007). Dual diagnosis of substance use and severe mental illness: the scope of the problem. *Journal of Dual Diagnosis*, 3, 59–62.

substance misuse services the prevalence of co-occurring mental health issues was between 35 and 89%¹⁴⁴.

In a study on primary care in the UK during 1993-1998 the prevalence of co-existing drug and psychiatric conditions increased by 62 per cent in England and Wales, with the rates of drug problems and psychoses, schizophrenia, and paranoia increasing by 147 per cent, 128 per cent and 144 per cent, respectively¹⁴⁵.

Another study, on mental health centres and substance misuse services in the UK, showed that three quarters of drug service users and 85 per cent of alcohol service users had mental health problems, mostly affective disorders and anxiety disorders. Approximately one third of the drug treatment population and half of the alcohol treatment population also had multiple morbidity¹⁴⁶. The costs of caring for service users with dual diagnosis are higher than for single conditions because of the need for greater service utilisation¹⁴⁷. Nearly 40 per cent of drug users had not received help for their mental health problems and just over 40 per cent of mental health service users reported drug use and/or hazardous or harmful levels of alcohol use in the past year. These individuals were perceived as being more aggressive, chaotic and less compliant with care plans^{7 148}.

Health and social impact of comorbid disorders

Those who live with both mental illness and substance misuse are at greater risk than those with a single disorder for poorer outcomes in multiple dimensions; they also contribute to higher treatment-related and societal costs in multiple settings². Apart from the direct negative effect of illicit substances on psychotic symptoms, there is an array of other medical and psychosocial issues impacted by substance use in people with disorders, such as schizophrenia. Thus, this group of people are susceptible to adverse physical health risks of a general nature, as well as elevated rates of hepatitis C and HIV/AIDS, largely consequent upon unsafe injecting techniques¹⁴⁹. Dual diagnosis patients are also more likely to experience a range of related social and relational problems, such as more criminality (including violence)¹⁵⁰; homelessness¹⁵¹; economic deprivation, unemployment; an increased rate of suicide¹⁵²; and poorer adherence to treatment¹⁵³ compared with individuals with mental health disorder alone.

¹⁴⁴ Hides, L., Elkins, K., Catania, L., Mathias, S., Kay-Lambkin, F., & Lubman, D. (2007). Feasibility and outcomes of an innovative cognitive-behavioural skill training programme for co-occurring disorders in the youth alcohol and other drug (AOD) sector. *Drug and Alcohol Review*, 26, 517–523.

¹⁴⁵ Crome, I. B. (1999) Substance Misuse and Psychiatric Comorbidity: towards improved service provision. *Drugs: Education, Prevention and Policy*, 6 (2), pp.151–174

¹⁴⁶ Weaver, T., et al (2003) Comorbidity of substance misuse and mental illness in community mental health and substance misuse services, *The British Journal of Psychiatry*, 183 (4), pp.304–313.8.

¹⁴⁷ Hoff, R. A. and Rosenheck, R. A. (1999) The cost of treating substance abuse patients with and without comorbid psychiatric disorders, *Psychiatric Services*, 50, pp.1309–1315

¹⁴⁸ Weaver, T., et al (2007) *Are Contingency Management Principles Being Implemented in Drug Treatment in England?*, Research Briefing 33, London, National Treatment Agency for Substance Misuse.

¹⁴⁹ Carey, M.P., Weinhardt, L.S., & Carey, K.B. (1995). Prevalence of infection with HIV among the seriously mentally ill: review of research and implications for practice. *Professional Psychology Research and Practice*, 26, 262–268.

¹⁵⁰ Cantor-Graae, E., Nordstrom, L.G., & McNeil, T.F. (2001). Substance abuse in schizophrenia: a review of the literature and study of correlates in Sweden. *Schizophrenia Research*, 48, 69–82.

¹⁵¹ Drake, R.E., Osher, F.C., & Wallach, M.A. (1991). Homelessness and dual diagnosis. *American Psychology*, 46, 1149–1158

¹⁵² Torrey, W.C., Drake, R.E., & Bartels, S.J. (1996). Suicide and persistent mental illness: a continual clinical and risk management challenge. In S.M. Soreff (Ed.), *Handbook for the treatment of the seriously mentally ill* (pp. 295–313). Cambridge, MA: Hogrefe & Huber Publishers.

¹⁵³ Drake, R.E., Osher, F.C., & Wallach, M.A. (1989). Alcohol use and abuse in schizophrenia: a prospective community study. *Journal of Nervous Mental Disorders*, 77, 408–414

Why is there such high comorbidity?

At present there remains much that is not known about the causal relationship between mental illness and substance misuse. However, it is widely assumed that people with mental illnesses use substances to 'self-medicate' either their symptoms or the side effects of their prescribed medication¹⁵⁴. Other factors that have been associated with substance misuse include dealing with boredom, depression, anxiety and insomnia, 'enhancement' such as 'to get high', social factors (such as 'because my friends do it')¹⁵⁵.

The importance of understanding motivations for use among people with a mental illness lies in the potential utility in both engagement and treatment. Clinicians are more likely to engage clients effectively if they can be seen to be trying to understand rather than simply condemn the substance use problem. Furthermore, dealing with the underlying motivators such as negative affect could conceivably reduce the drive for use¹².

Addressing the problem

The provision of services to people with dual diagnosis has long been challenged by organisational separation between mental health and drug and alcohol service leading to fragmented and ineffective care¹⁵⁶. Most clients are unable to navigate the separate systems or make sense of disparate messages about treatment and recovery. Often they are excluded or extruded from services in one system because of the comorbid disorder and told to return when the other problem is under control. Vast amount of research has gone into exploring evidence-based model programmes for treating this particular sub-group¹⁵⁷. Over time, integrated dual diagnosis treatment services and programmes have been steadily developed, refined and evaluated¹⁵⁸.

Dual diagnosis treatments combine or integrate mental health and substance abuse interventions at the level of the clinical interaction. Hence integrated treatment means that the same clinicians or teams of clinicians, working in one setting, provide appropriate mental health and substance abuse interventions in a coordinated fashion. For the individual with a dual diagnosis, the services appear seamless, with a consistent approach, philosophy, and set of recommendations. This increases the likelihood that the experience of the client and their family is person-centred or family-centred.

The goal of dual diagnosis interventions is recovery from two serious illnesses. In this context, "recovery" means that the individual with a dual diagnosis learns to manage both illnesses so that he or she can pursue meaningful life goals.

¹⁵⁴ Pawsey B., et al (2011) Psychological treatments for comorbidity across the life course. *Mental Health and Substance Use*. 4;72-82.

¹⁵⁵ Spencer, C., Castle, D., & Michie, P. (2002). Motivations that maintain substance use among individuals with psychotic disorders. *Schizophrenia Bulletin*, 28, 233–247.

¹⁵⁶ Ridgely MS, Osher FC, Goldman HH, et al: Executive Summary: Chronic Mentally Ill Young Adults With Substance Abuse Problems: A Review of Research, Treatment, and Training Issues. Baltimore, University of Maryland School of Medicine, Mental Health Services Research Center, 1987

¹⁵⁷ Drake RE, Essock SM, Shaner A, et al: Implementing dual diagnosis services for clients with severe mental illness. *Psychiatric Services* 52:469–476, 2001

¹⁵⁸ Drake RE, Wallach MA: Dual diagnosis: 15 years of progress. *Psychiatric Services* 51:1126–1129, 2000

Critical components of an integrated treatment service^{159 160}

Several components of integrated programmes can be considered evidence-based practices because they are almost always present in programmes that have demonstrated good outcomes in controlled studies and because their absence is associated with predictable failures¹⁶¹.

- *Treatment aims*

It is necessary to keep in mind that there are several treatment aims. An overarching aim is to minimise harm associated with lifestyle choices related to substance misuse and treatment adherence. To achieve this, clinicians should educate clients about various aspects of mental illness, adherence to medications, key facts and risks about substance misuse and other related topics. In addition to this, clinicians should educate clients about the role of the health care system and other supportive agencies.

- *Assessment*

Given the high prevalence, it is important to assess all mental health clients for substance misuse. It is important to inquire about and document the presenting problems, substances being used, awareness of the problems, harm reduction knowledge, level of motivation to reduce substance use, and family involvement. Previous psychiatric history, medication use and personal history are also important to ascertain. Assessment should be viewed as an on-going process rather than a one-time event; for example mental status examinations, substance assessment and risk assessments need to be repeated regularly.

- *Staged interventions*

Stages of treatment include:

Forming a trusting relationship with the client. Clinicians should express empathy about the client's situation and discuss any concerns they might have. Engagement with the client should always be respectful, optimistic and non-confrontational. It is important to discuss issues of confidentiality, stigma and medications including side effects.

- Treatment should be active rather than passive. Clinicians need to adapt goals, clarify aims, develop strategies to cope with triggers and cravings, provide on-going assessment and reassessment and continue with motivational interviewing to overcome hurdles. Helping the engaged client develop the motivation to become involved in recovery-oriented interventions. Client should acquire skills and support for controlling illnesses and pursuing goals through social skills training, self-help groups and education sessions about the interaction between psychotropic medications, mental illness and substance misuse.

¹⁵⁹ Drake R.E., et al (2004) Implementing dual diagnosis services for clients with severe mental illness. The J of lifelong learning in psych vol II, no. 102-110

¹⁶⁰ Cleary M. et al (2008) Promoting dual diagnosis awareness in everyday clinical practice. J of Psychosocial Nursing 46;43-49

¹⁶¹ Mercer-McFadden C, Drake RE, Brown NB, et al: The community support program demonstrations of services for young adults with severe mental illness and substance use disorders, 1987–1991. Psychiatric Rehabilitation Journal 20(3):13–24, 1997

- Helping the client in stable remission develop and use strategies for maintaining recovery. To reduce the likelihood of relapse the clinician needs to identify and address high-risk situations for the clients resorting to substance misuse. This includes rehearsing coping strategies to resist using substances and recognising personal signs of mental health deterioration are all beneficial. In addition to this it is necessary to have a care plan in the event of a relapse, as well as following hospital discharge. Consideration needs to be given to problem solving and social skills training so clients can develop relationships with abstinent friends to minimize social pressures to use substances. Meaningful activities and social support networks are also important for relapse prevention.

Clients do not move linearly through stages. They sometimes enter services at advanced levels, skip over or pass rapidly through stages, or relapse to earlier stages. They may be in different stages with respect to mental illness and substance abuse. Nevertheless, the concept of stages has proved useful to programme planners and clinicians because clients at different stages respond to stage-specific interventions.

- *Care plans*

A care plan helps structure treatment management and ensures that treatment remains on track. Clinicians should negotiate with the client, family members, and treatment providers and agree on clear and realistic treatment goals. These should be broken down to short-term achievable targets, and it should be noted who is responsible for what aspect of management in which agency, including the evaluation of outcomes.

- *Cycle of change*

To decrease frustration and reduce the risk of confrontation, it is important that staff become familiar with the fluid nature and phases of people's intention to change behaviour. There are 5 stages of readiness to change:

- Pre-contemplation (not considering change)
- Contemplation (considering change)
- Preparation (deciding to change)
- Action (changing behaviour)
- Maintenance (maintaining achievements)

These key, practical concepts are reminders that returning to an earlier phase or relapse is always possible. Change often occurs over time, perhaps over several admissions. It is important when planning an intervention to ensure consistency with the stages of treatment model; engagement, persuasion, active treatment and relapse prevention.

- *Assertive outreach*

Many clients with a dual diagnosis have difficulty linking with services and participating in treatment. Effective programmes engage clients and members of their support systems by providing assertive outreach, usually through a combination of

intensive case management and meetings in the client's residence¹⁶². For example, homeless persons with dual diagnoses often benefit from outreach, help with housing, and time to develop a trusting relationship before participating in any formal treatment. These approaches enable clients to gain access to services and maintain needed relationships with a consistent programme over months and years. Without such efforts, noncompliance and dropout rates are high.

- *Motivational interventions*

Most dual diagnosis clients have little readiness for abstinence-oriented treatment. Many also lack motivation to manage psychiatric illness and to pursue employment or other functional goals. Effective programmes therefore incorporate motivational interventions that are designed to help clients become ready for more definitive interventions aimed at illness self-management¹⁶³. For example, clients who are so demoralized, symptomatic, or confused that they mistakenly believe that alcohol and cocaine are helping them to cope better than medications require education, support, and counselling to develop hope and a realistic understanding of illnesses, drugs, treatments, and goals. Motivational interventions involve helping the individual identify his or her own goals and to recognize, through a systematic examination of the individual's ambivalence, that not managing one's illnesses interferes with attaining those goals¹⁶⁴. Research has demonstrated that clients who are not motivated can be effectively helped with motivational interventions¹⁶⁵.

- *Counselling*

Once clients are motivated to manage their own illnesses, they need to develop skills and supports to control symptoms and to pursue an abstinent lifestyle. Effective programmes provide some form of counselling that promotes cognitive and behavioural skills at this stage. The counselling takes different forms and formats, such as group, individual, or family therapy or a combination¹⁶⁶. Few studies have compared specific approaches to counselling, although one study did find preliminary evidence that a cognitive-behavioural approach was superior to a 12-step approach¹⁶⁷.

- *Social support interventions*

In addition to helping clients build skills for managing their illness and pursuing goals, effective programmes focus on strengthening the immediate social environment to help them modify their behaviour. These activities, which recognize the role of social networks in recovery from dual disorders, include social network or family interventions.

¹⁶² Mercer-McFadden C, Drake RE, Brown NB, et al: The community support program demonstrations of services for young adults with severe mental illness and substance use disorders, 1987–1991. *Psychiatric Rehabilitation Journal* 20(3):13–24, 1997

¹⁶³ Barrowclough C, Haddock G, Tarrrier N, et al: Cognitive-behavioral intervention for clients with severe mental illness who have a substance misuse problem. *Psychiatric Rehabilitation Skills* 4:216–233, 2000

¹⁶⁴ Miller W, Rollnick S: *Motivational Interviewing: Preparing People to Change Addictive Behavior*. New York, Guilford, 1991

¹⁶⁵ Carey KB, Maisto SA, Carey MP, et al: Measuring readiness-to-change substance misuse among psychiatric outpatients: I. Reliability and validity of self-report measures. *J Stud Alcohol* 62:79–88, 2001

¹⁶⁶ Mueser KT, Drake RE, Noordsy DL: Integrated mental health and substance abuse treatment for severe psychiatric disorders. *Journal of Practical Psychiatry and Behavioral Health* 4:129–139, 1998

¹⁶⁷ Jerrell JM, Ridgely MS: Comparative effectiveness of three approaches to serving people with severe mental illness and substance abuse disorders. *Journal of Nervous and Mental Disease* 183:566–576, 1995

- *Long-term perspective*
Effective programmes recognize that recovery tends to occur over months or years in the community. People with severe mental illness and substance abuse do not usually develop stability and functional improvements quickly, even in intensive treatment programmes. Instead, they tend to improve over months and years in conjunction with a consistent dual diagnosis programme. Effective programmes therefore take a long-term, community based perspective that includes rehabilitation activities to prevent relapses and to enhance gains.
- *Comprehensiveness*
Learning to lead a symptom-free, abstinent lifestyle that is satisfying and sustainable often requires transforming many aspects of one's life, such as habits, stress management, friends, activities, and housing. Inpatient hospitalization, assessment, crisis intervention, medication management, money management, laboratory screening, housing, and vocational rehabilitation incorporate special features that are tailored specifically for dual diagnosis patients. For example, housing and vocational programmes can be used to support the individual with a dual diagnosis in acquiring skills and supports needed for recovery.
- *Diversity*
People with a dual diagnosis are not a homogenous group and may have multiple impairments. The key to success is individualized treatment plans that can be adapted to address difference in client age, gender, culture, and spirituality which traditional agencies may not have taken into account¹⁶⁸.

Understanding the particular needs of more vulnerable groups, for example, homeless people, teenagers, and older people. Consideration to this heterogeneity may enhance the various combinations of psychological, social, and pharmacological treatments matched to the client's needs¹⁶⁹.

- *Agency collaboration*
Effective services for dual diagnosis are contingent on positive and constructive collaboration across a wide range of agencies; health care, social, justice and community services.

Implementation barriers & strategies¹⁶

Although integrated dual diagnosis services and other evidence-based practices are widely advocated, they are rarely offered in routine mental health treatment settings and implementation is associated with a host of barriers.

- *Policy*
Often policies related to organizational structure, financing, regulations, and service delivery militate against the functional integration of mental health and substance abuse services¹⁷⁰. These services are usually provided under separate departments

¹⁶⁸ Green A.I., et al (2007) Schizophrenia and co-occurring substance use disorder. *American Journal of Psychiatry*, 164, 402-408.

¹⁶⁹ Drake R.E., et al (2005) Future directions in preventing relapse to substance abuse among clients with severe mental illness. *Psychiatric Services*, 56, 1297-1302

¹⁷⁰ Ridgely M, Goldman H, Willenbring M: Barriers to the care of persons with dual diagnoses: organizational and financing issues. *Schizophrenia Bulletin* 16:123-132, 1990

with separate funding streams, enabling legislation, information systems and service criteria and protocol.

Commonly used system-level strategies include building a consensus around the vision for integrated services and then conjointly planning; specifying a model; implementing structural, regulatory, and reimbursement changes; establishing contracting mechanisms; defining standards; and funding demonstration programs and training initiatives¹⁷¹.

Anecdotal evidence indicates that blending mental health and substance abuse funds appears to have been a relatively unsuccessful strategy, especially early in the course of system change. Fear of losing money to cover non-traditional populations often leads to prolonged disagreements, inability to develop consensus, and abandonment of other plans. As a less controversial, preliminary step, the mental health service often assumes responsibility for comprehensive care, including substance abuse treatment, for persons with severe mental illness, while the substance abuse service assists by pledging to help with training and planning.

- *Programme delivery*

At the local level, administrators of clinics, centres, and programmes have often lacked the clear service models, administrative guidelines, contractual incentives, quality assurance procedures, and outcome measures needed to implement dual diagnosis services. In addition to this, many experience difficulty in hiring a skilled workforce with experience in providing dual diagnosis interventions.

At the level of the mental health clinic or programme, the fundamental task is to begin recognizing and treating substance misuse rather than ignoring it or using it as a criterion for exclusion. After consensus-building activities to prepare for change, staff will need training and supervision to learn new skills and reinforcement for acquiring and using these skills effectively. One common strategy is to appoint a director of dual diagnosis services whose job is to plan and oversee the training of staff, the integration of substance abuse awareness and treatment into all aspects of the mental health programme, and the monitoring of these activities through quality assurance activities and outcome data. Experts identify the importance of having a single leader for program change¹⁷².

- *Clinical level*

Although an integrated clinical and practical approach to dual diagnosis treatment has been clearly defined for more than a decade, educational institutions rarely teach this approach. Consequently, mental health clinicians typically lack training in dual diagnosis treatment and have to rely on informal, self-initiated opportunities for learning current interventions¹⁷³. They often avoid diagnosing substance abuse when they believe that it is irrelevant, that it will interfere with performance outcomes and funding, or that they cannot treat it.

¹⁷¹ Co-occurring Psychiatric and Substance Disorders in Managed Care Systems. Rockville, Md, Mental Health Services, 1998

¹⁷² Corrigan PW: Wanted: champions of rehabilitation for psychiatric hospitals. *American Psychologist* 40:514–521, 1995

¹⁷³ Carey KB, Purnine DM, Maisto SM, et al: Treating substance abuse in the context of severe and persistent mental illness: clinicians' perspectives. *Journal of Substance Abuse Treatment* 19:189–198, 2000

To address barrier, mental health clinicians need to acquire knowledge and a core set of skills related to substance abuse that includes assessing substance abuse, providing motivational interventions for clients who are not ready to participate in abstinence-oriented treatment, and providing counselling for those who are motivated try to maintain abstinence. Because substance abuse affects the lives of the great majority of clients with severe mental illness— as a comorbid disorder—all clinicians should learn these basic skills. Otherwise substance abuse problems will continue to be missed and untreated in this population.

- *Client and family*

Clients and their families rarely have good information about dual diagnosis and appropriate services. Few programmes offer psycho educational services related to dual diagnosis, although practical help from families plays a critical role in recovery¹⁷⁴. Family members are often unaware of substance abuse, blame all symptoms on drug abuse, or attribute symptoms and substance use to wilful misbehaviour. Supporting family involvement is an important but neglected role for clinicians.

Clients often deny or minimize problems related to substance abuse and, like other substance abusers, believe that alcohol or other drugs are helpful in alleviating distress. They may be legitimately confused about causality because they perceive the immediate effects of drugs rather than the intermediate or long-term consequences. The net result is that the individual lacks motivation to pursue active substance abuse treatment, which can reinforce clinical inattention.

To address this barrier, clients and family members need access to accurate information. Otherwise their opportunities to make informed choices, to request effective services, and to advocate for system changes are severely compromised.

Vulnerable groups

- *Adolescents and young adults*

Adolescence and young adulthood is the stage of life when psychiatric disorders are most often diagnosed. Depression and disruptive behaviour disorders are typically diagnosed in younger adolescents and often precede and predispose young people to substance misuse. Serious mental illnesses that involve bipolar and schizophrenia are most commonly diagnosed in late adolescence/early adulthood. 50% of lifetime mental illnesses start by age 14 and 75% by age 24^{175 176}. The incidence of co-morbid mental illness and substance misuse disorders among adolescents and young adults is a significant public health issue, resulting in tremendous hardship and devastating effects upon their families¹⁷⁷. The onset of mental illness can interrupt the course of cognitive and social emotional development. Combined with a substance misuse problem, it can interfere with their ability to complete school establish and maintain healthy relationships, find and maintain employment and even live

¹⁷⁴ Clark RE: Family support and substance use outcomes for persons with mental illness and substance use disorders. *Schizophr Bull* 27:93–101, 2001

¹⁷⁵ Crowley, T. & Riggs P. (1999) Adolescent substance use disorder with conduct disorder and comorbid conditions. Adolescent drug abuse: clinical assessment and therapeutic interventions, NIDA research monograph no. 156

¹⁷⁶ Hoffman N., et al (2001) Co-occurring disorders among adolescent treatment populations. Dual diagnosis recovery network

¹⁷⁷ National alliance on mental illness New Hampshire: Reclaiming our future – a pathway for treating co-occurring mental health and substance use disorders in New Hampshire’s adolescents and young adults.

independently.

Untreated co-morbid disorders in adolescents and young adults can lead to a downward spiral across the lifespan, increasing high users of medical and social resources. Such individuals are more likely to have frequent and or extended hospitalizations, over-use of emergency departments, difficulty maintaining housing stability and experience homelessness, have repeated involvement with the juvenile justice, criminal justice and child protection service, more chronic health problems, increased vulnerability to HIV infection, suicide and violence¹⁷⁸. Therefore, early detection and treatment is essential to halting the progression of negative outcomes for these young people and their families.

Challenges to accessing treatment include, the stigma associated with both disorders which impedes treatment seeking behaviour before a crisis occurs, lack of appropriate workforce and skill set and lack of integrated treatment and funding for co-morbid disorders.

The Scientific Advisory Board (SAB) carried out extensive research in New Hampshire to help address many of these challenges³². The SAB developed recommendations in the following areas:

- Establish a conceptual framework for providers across disciplines to work from standardizing terminology and identifying resources. To ensure continuity of care across the systems.
 - Identify valid screening and assessment tools and evidence-based practises proven effective for adolescents and young adults.
 - Develop strategies to support and assist changes in the system that would facilitate the adoption and implementation of screening, assessment and appropriate integrated treatments.
-
- *Older people*

In the UK, a significant number of people do develop dementia or depression in old age. Between 10–16% of people over 65 have depression. An estimated 2–4% have severe depression. Older people living alone or in residential/nursing care and those with physical illnesses and/or disabilities are more at risk, with some 40% affected by depression¹⁷⁹. Older people living alone or in residential/nursing care and those with physical illnesses and/or disabilities are more at risk.

An estimated 4%–23% of older adults seen by medical staff have an alcohol problem. Alcohol problems are more common in older men. Although alcohol abuse is a problem for people of all ages, it is more likely to go unrecognised among older people. About one in three older people with alcohol problems only start drinking excessively in later life. Reasons for alcohol abuse in older age include bereavement and other losses, loneliness, physical ill health, disability and pain, loss of independence, boredom and depression, which is also linked to the other factors.

¹⁷⁸ New Freedom Commission on Mental Health (2003). Achieving the promise: transforming mental health care in America. Final report, Rockville, MD: U.S. Dept of Health and Human services

¹⁷⁹ <http://www.mentalhealth.org.uk/help-information/mental-health-a-z/O/older-people/>

Retirement may also provide more opportunities for drinking too much. Approximately 10–30% of older people who abuse alcohol become depressed. They are also at greater risk of suicide³⁶.

Diagnosis and assessment

Diagnosis of co-occurring substance misuse and mental illness among older adults is hampered by the lack of validated instruments for this age group particularly regarding diagnostic criteria that are not relevant to them because of changes in their social roles and functioning and reduced levels of tolerance related to age-related changes in metabolism.

Diagnosis of substance misuse among older people is also made difficult due to reluctance of patients to self-disclose substance use, by family members who do not recognise it and by health care workers who discount the significance of these disorders among this group.

Despite the lack of validated instruments assessment can also include: physical examination, blood investigations and urine drug screening and breathalyser reading.

Treatment

Treatment of older people with co-occurring disorders may be complicated by dementia and other forms of cognitive impairment that make it hard for them to follow instructions or to utilise cognitive-behavioural strategies¹⁸⁰. Despite these changes in cognitive and physical functioning associated with aging, several studies have shown that older adults are just as likely to engage in treatment as younger adults and in some cases, may be more amenable to treatment¹⁸¹.

Prevention and early intervention

Without effective prevention and treatment, a range of disabilities and impairment can result from substance misuse and mental illness. Hampered independence and community-based functioning, a compromised quality of life, poor health outcomes, cognitive impairment, increased mortality and increased caregiver stress are potential negative outcomes resulting from co-morbid disorders¹⁸². Older people with mental illness or/and substance misuse are also at risk for receiving inadequate and inappropriate treatment and care¹⁸³.

Recommendations to improve treatment planning^{39 184}

- Treatment staff in substance misuse and mental health programmes should be trained in the assessment and diagnosis of these disorders among older people – particularly regarding factors that need to be modified such as diagnostic criteria and treatment approaches.

¹⁸⁰ Patterson T.L. & Jeste D.V. (1999) The potential impact of the baby-boom generation on substance abuse among elderly persons. *Psychiatric Services*, 50(9), 1184-1188

¹⁸¹ Grella C.E. (2009) Older adults and co-occurring disorders. Prepared for: Alcohol and drug policy institute (UCLA Integrated substance abuse programmes)

¹⁸² USDHHS. *Mental Health: A report of the surgeon general*. Rockville, MD: U.S. Department of Health and Human Services; 1999

¹⁸³ Bartels S.J (2002). Quality, costs, and effectiveness of services for older adults with mental disorders: a selective overview of recent advances in geriatric mental health services research. *Current opinion in Psychiatry*. 15 (4): 411-416.

¹⁸⁴ Bartels S.J, et al (2005). Substance abuse and mental health among older Americans: the state of the knowledge and future directions. Prepared for Older American Substance abuse and mental health technical assistance center - Substance abuse and mental health services administration Rockville, Maryland.

- Treatment providers might consider providing tailored programmes to address the risk factors commonly faced by older people such as poor social supports, social isolation, death of a spouse or loved one and lack of support from relatives or friends.
- As older people are usually high users of primary health care, clinicians should be trained to screen for and diagnose dual diagnosis in older patients and provide appropriate interventions or referrals to treatment services.
- Deliver screening, educational approaches and brief interventions through a variety of settings (e.g. health fairs, housing estates, older people day community centres, faith settings) which may be an effective and cost-effective approach for intervening with older people at risk for co-occurring disorders.
- Ensure services are equitable for example provision of bilingual services, bicultural staff, disability access and easily accessible.

6. What does the evidence say are the effective interventions to support people with a mental health problem who are in the criminal justice system (including the youth justice system)?

National context

A significant proportion of crime is committed by offenders who have multiple problems. Evidence tells us that:

- 64% of newly sentenced prisoners report using a drug during the four week period before custody (30% heroin, 28% crack cocaine)¹⁸⁵.
- 44% of offenders assessed in 2008 had problems with alcohol misuse which may have required treatment¹⁸⁶.

A study of prisoners¹⁸⁷ also found that:

- 37% of prisoners have stated that they will need help finding a place to live when they are released from prison.
- 12% said they had a mental illness or depression as a long-standing illness.
- 20% reported needing help with an emotional or mental health problem.
- 24% said they had been taken into care as a child.
- 47% said they had no qualifications.
- 13% said that they have never had a paid job.

The 1998 publication of a survey for the Office for National Statistics on psychiatric morbidity among prisoners¹⁸⁸ was a comprehensive attempt to provide robust baseline information about the prevalence of psychiatric problems among male and female, remand and sentenced prisoners.

¹⁸⁵ Compendium of reoffending statistics and analysis, published November 2010, available at <http://www.justice.gov.uk/publications/compendium-reoffending.htm>.

¹⁸⁶ A compendium of Research and Analysis on the Offender Assessment System, 2006–2009, published by Ministry of Justice, 2009.

¹⁸⁷ From a sample of 1,435 reception prisoners sentenced to between one month and four years in prison, in England and Wales, in 2005/06. Compendium of reoffending statistics and analysis, published November 2010, available at <http://www.justice.gov.uk/publications/compendium-reoffending.htm>.

¹⁸⁸ Singleton N et al, 1998, *Psychiatric morbidity among prisoners in England and Wales*

Some key findings from this survey report showed that:

- Over 90% of prisoners had one or more of the five psychiatric disorders studied (psychosis, neurosis, personality disorder, hazardous drinking and drug dependence).
- Remand prisoners had higher rates of mental disorder than sentenced prisoners.
- Rates of neurotic disorder in remand and sentenced prisoners were much higher in women than in men.

These findings highlight some of the most important factors associated with crime as well as the size and scale of the problem. We must tackle the drug dependency, mental illness and poor education which fuel criminal behaviour.

In addition, there are specific concerns about certain groups, such as women and people from black and minority ethnic communities and young offenders¹⁸⁹. The proportion of women in prison has increased dramatically over the past ten years and people from black and minority ethnic communities are over represented in the criminal justice system. The rate of self-harm and suicide amongst women in prison, in particular, greatly exceeds that of the general population.

The prison population has soared in the last decade. The government has acknowledged the need to improve mental health care for prisoners and the NHS is now responsible for prison health care. It aims to give 'prisoners access to the same quality and range of health care services as the general public receives from the National Health Service.

Young offenders

Of the 87,531 people in prison on 31 March 2012, 9,198 were young people (aged 15-20). Children who end up in custody are three times more likely to have mental health problems than those who do not. They are also very likely to have more than one mental health problem, to have a learning disability, to be dependent on drugs and alcohol and to have experienced a range of other challenges. Many of these needs go unrecognized and unmet.

Key reports

Lord Bradley's review¹⁹⁰ on improving mental health and learning disability outcomes for offenders have been acted upon with the aim of ensuring that offenders have the same access to mental health services as the rest of the population and that mental health issues are picked up as early as possible in their interaction with the criminal justice system throughout the offender pathway. This review has been charged with making recommendations for national policy and practice and covers diversion for children and young people as well as adults.

The Ministry of Justice Green Paper¹⁹¹ has supported this approach. The Department of Health, the Ministry of Justice and the Home Office are working with the NHS, which has funding and commissioning responsibility for diversion services. Together, they will identify a number of diversion pathfinders from existing services that will help to shape best practice, quantify the benefits and develop appropriate quality standards. In addition, further work will support development of mainstream service capacity to treat those referred by diversion services.

¹⁸⁹ Centre for Mental Health http://www.centreformentalhealth.org.uk/criminal_justice/issue_overview.aspx

¹⁹⁰ The Bradley Report

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_098699.pdf

¹⁹¹ Breaking the Cycle: Effective Punishment, Rehabilitation and Sentencing of Offenders (Ministry of Justice 2010)

The 'Diversion – a better way for criminal justice and mental health'¹⁹² report focused largely on diversion at the key decision-making stages of the criminal justice system. These stages cover the critical steps after an offence has been committed, when a series of decisions are taken within the criminal justice system on charging, remand, sentencing and disposal. It is in this territory that mental health diversion and liaison schemes concentrate their efforts, working with the appropriate criminal justice agencies to strike an appropriate balance between the administration of justice and the meeting of mental health needs. This report provides an analysis of the case for diversion, with a particular focus on value for money; this report focuses on adults only.

The Department of Health No health without mental health: implementation framework¹⁹³ reinforces these approaches and sets out what local criminal justice organisations can do to improve health outcomes of offenders in the judicial system.

Putting these policies/recommendations into practice presents a significant challenge. Overcrowding, lack of staff skilled in dealing with mental health problems and inability to effectively manage mental health problems have been identified as some of the key problems which need to be addressed.

As mental health service providers develop mental health services in prison, services are required to work in a collaborative way, to ensure the efficiency of those services, that the service provision is formed according to the needs of the population it served, and that [clear pathways of care](#) are created to ensure that prisoners get the care they need in a timely fashion.

Approaches & interventions

- *Diversion*¹³

A high proportion of offenders have mental health needs. The criminal justice system is not always well placed to handle the complex problems that this can create. An important role at the interface between criminal justice and mental health is therefore assigned to diversion, loosely defined as a means of ensuring that people with mental health problems who enter the criminal justice system are identified and directed towards appropriate mental health care, particularly as an alternative to imprisonment.

The evidence indicates that well-designed arrangements for diversion have the potential to yield multiple benefits, including:

- Cost and efficiency savings within the criminal justice system;
- Reductions in re-offending;
- Improvements in mental health.

Taken together, these benefits constitute a powerful case for diversion on value for money grounds. There is a particularly strong case for diverting offenders away from short sentences in prison towards effective treatment in the community. Diverting people towards effective community-based services will improve their mental health.

¹⁹² Diversion - A better way for criminal justice and mental health. Report: Sainsbury centre for mental health <http://www.centreformentalhealth.org.uk/pdfs/Diversion.pdf>

¹⁹³ No health without mental health: implementation framework (DH 2012) <http://www.dh.gov.uk/health/files/2012/07/No-Health-Without-Mental-Health-Implementation-Framework-Report-accessible-version.pdf>

It can also reduce the prevalence of other risk factors such as substance misuse and improve the effectiveness of interventions aimed at other influences on offending.

A major challenge in light of these benefits is the absence of a clear national policy framework. Other issues include, diversion services have developed in a piecemeal and haphazard way; many schemes are insecurely funded and there is an unacceptably wide degree of variation in their ways of working. This is further underpinned by the shortage of research findings from well-conducted studies.

- *Potential benefits of diversion schemes*¹³

The first organised scheme for diversion in England and Wales was implemented as a pilot in 1989.

Following the 1992 Reed review of health and social care for mentally disordered offenders and associated Home Office guidance there was a substantial expansion of such services. Ten years later, about 150 diversion programmes were in existence around the country.

In the first instance diversion schemes focused mainly on identifying cases of severe mental illness among those coming into contact with the criminal justice system and bringing about their transfer to psychiatric hospitals. However, since only a small number of individuals required this type of care, many schemes came to focus more on a liaison function, signposting people to mental health and other services in the community and in prisons.

It is important to note that routinely collected information on outcomes and effectiveness is largely non-existent and in consequence all schemes find it difficult to evaluate their success especially as there is no national standard minimum data set in operation.

However, studies have been undertaken in relation to three areas of potential success for diversion and liaison services outlined below:

1. *Improvements in the identification of mental illness among people coming into contact with the criminal justice system.*

Improvements in identifying mental ill health have come about through the greater use of screening procedures by diversion schemes, usually by examining files for identifying markers such as previous contact with mental health services. Better identification can also result from allowing referrals from multiple sources, including self-referral, and from introducing diversion schemes at multiple points in the criminal justice system, most obviously at police stations as well as courts. Where this has been done, it has been found that a police-based service can identify seriously ill people who would otherwise be returned uncharged to the community and would not therefore have received an assessment by a court scheme¹⁹⁴. This study suggested that intervening at this early stage could have a preventive impact on further offending.

¹⁹⁴ James, D. (2000) Police station diversion schemes: role and efficacy in central London. *Journal of Forensic Psychiatry*, 11 (3) 532-555.

2. *Improvements in the criminal justice process for offenders with mental health problems, such as quicker handling of cases.*

There are various ways in which diversion and liaison schemes can support criminal justice agencies and improve the general efficiency of the criminal justice system, including:

- Increasing awareness of mental health issues among criminal justice staff.
- Reducing the risk of dangerous or disruptive behaviour in custody through the correct or earlier identification of mental health problems among prisoners.
- Reducing the use of remand, for example by speeding up the transfer of severely ill prisoners to hospital or helping those with less serious mental health needs to remain in the community on bail.
- Reducing delays in the provision of psychiatric assessments.
- Facilitating non-custodial sentences for offenders with mental health needs in appropriate cases, thereby reducing the demand for prison places.

3. *Improvements in longer-term outcomes, particularly in terms of better mental health and reduced re-offending.*

Few studies have sought to assess the longer-term outcomes of diversion and liaison schemes in this country. However, a comprehensive study of hospital diversion, compared outcomes for a sample of 214 cases admitted to hospital through court diversion schemes with those for a matched sample of 214 compulsory admissions from the general population under the Mental Health Act¹⁹⁵. The main findings were strongly positive. In particular, the diverted group:

- Were just as likely as the comparison group to complete their admissions.
- Had similar lengths of stay in hospital.
- Were no more likely to be violent or to engage in substance misuse in hospital.
- Achieved a similar improvement in mental health by the time of discharge.
- Were not re-admitted any more quickly.

The diverted group were more likely than the comparison group to be convicted in a two-year period after discharge, but there were nevertheless significant reductions in numbers of convictions during this period compared with the two years before admission. The re-conviction rate among the diverted group in the two years after discharge was only 28%, compared with general re-conviction rates, at the time of this study, of 56% among discharged prisoners and 58% among offenders placed on community penalties¹⁶.

• *Potential cost savings of diversion*¹³

The main areas of potential savings in the criminal justice system which may be promoted by diversion schemes are reductions in:

- The number of arrests
- The number of prosecutions
- The use of remand

¹⁹⁵ James, D., et al (2002) *Outcome of Psychiatric Admission through the Courts*. London: Home Office.

- The number of formal psychiatric reports
- The number of ineffective court hearings and other causes of delay in the administration of justice
- The number of prison sentences, because of diversion to appropriate community alternatives

There are also a number of ways in which diversion schemes can help to speed up the administration of justice. This is desirable both as an end in itself and because it can contribute to cost savings, such as reducing the amount of time defendants spend on remand. But there is no obvious way of attaching a monetary value to the first of these sources of improvement, which implies that the total benefits of diversion will be understated.

Based on conservative assumptions, it is estimated that this will lead to savings in crime-related costs of over £20,000 per case, including savings to the criminal justice system of up to £8,000 and benefits from reduced re-offending valued at around £16,000.

- *Recommendations - to address the shortcomings in the provision of diversion*¹³
National coverage combined with greater uniformity in standard of provision
 - A Diversion and Liaison Team for people with mental health problems who come into contact with the criminal justice system should be established in every primary care trust (PCT) area in England. These teams should be supported by a national statement of policy and associated implementation guidance.
- Team structure and composition*
- Teams should be multi-disciplinary, including some expertise in dual diagnosis, in outreach work and in housing and employment issues. They should also have a psychiatrist's input.
- Written agreements*
- There are many advantages to be gained by formalising relationships in this way, including greater clarity of aims and objectives, improved accountability and an associated requirement for better data, particularly for monitoring purposes.
- Multi-agency working*
- The effectiveness of diversion and liaison teams depends to a large degree on establishing and maintaining good relationships with a wide range of other organisations and agencies.
- Funding*
- Diversion and liaison services are very largely funded from mental health budgets (NHS and, to a lesser extent, social services). There are very strong arguments for joint funding from mental health and criminal justice budgets.
 - The work of diversion and liaison schemes can yield substantial financial benefits for the criminal justice system, both in the short term, by improving efficiency in the administration of justice, and in the longer term, by reducing re-offending.

All-stage diversion

- Diversion schemes should operate at all stages of the criminal justice pathway, from arrest through to sentencing and beyond, rather than concentrating their activities at a single location in the criminal justice system. This would provide support for individuals from the time of arrest, as they pass through the courts and after they have been sentenced.
- In the case of offenders who receive a prison sentence, the role of teams will be to liaise with prison in-reach services. For those on community orders, teams will need to work closely with probation staff.
- The provision of care in this way has a number of advantages, including greater continuity of support and the establishment of closer relationships with individual offenders. This in turn is likely to lead to better engagement with services.

Identification and assessment

- Diversion and liaison teams should extend the use of pro-active methods of identifying potential clients, including screening of all selected groups of offenders i.e. women, young people and repeat offenders.
- Dual diagnosis, i.e. mental ill health co-existing with substance misuse, is extremely common among offenders. Both of these factors support a case for close joint working between drug intervention programme teams and diversion teams. Possibilities include the use of jointly conducted assessments or the up-skilling of workers in both teams so that either is capable of carrying out assessments that cover both mental illness and substance misuse.
- In addition, there is the need to improve the identification of mental illness by police officers, court officials and other criminal justice staff. This can be done through staff training on mental health awareness and /or extend the questions relating to mental health that are routinely asked within the criminal justice system.

Training for criminal justice staff

- Provision training on mental health awareness is clearly good practice and can help to improve the identification of offenders with mental health problems and their management as they go through the criminal justice system. Training should be seen by all diversion and liaison teams as part of their core business, with explicit provision for this being included in the contracts or service-level agreements with criminal justice agencies.

Influencing decisions in the criminal justice system

- All diversion and liaison teams should provide recommendations as well as information to criminal justice agencies, in relation to decisions on charging, remand, sentencing and disposal.

Engagement with services

- The effectiveness of diversion depends critically on successfully engaging offenders with local services on a continuing basis.
- Diversion and liaison teams should undertake outreach work as a core part of their business to ensure that their clients engage satisfactorily with local services. All diversion and liaison teams should undertake outreach work as a core part of their business to ensure that their clients engage satisfactorily with local services paying attention to particular needs of some groups i.e. cultural awareness in some BME groups.

Improving the evidence base

- Carry out more research and improve data collection on psychiatric morbidity among all offenders to develop more reliable evidence on diversion and improve knowledge of cost-effectiveness.

The Bradley report¹¹

This report was an independent review undertaken by Lord Keith Bradley on behalf of the Government to:

- Examine the extent to which offenders with mental health problems or learning disabilities could, in appropriate cases, be diverted from prison to other services and the barriers to such diversion.
- Make recommendations to government, in particular on the organization of effective court liaison and diversion arrangements and the services needed to support them.

Recommendations from this report included:

Early intervention, arrest & prosecution

- All staff in schools and primary healthcare, should have mental health training in order to identify individuals (children and young people in particular) needing help and refer them to specialist services.
- All Youth Offending Teams must include a suitably qualified mental health worker who is responsible for making appropriate referrals to services as they play a key role in assessing young people, providing preventative programmes for those identified as being at risk of offending.
- The police are usually the first point of contact with the criminal justice system and there is an early opportunity through police intervention and liaison to engage services and potentially avoid future problems. The police stage is currently the least developed in the offender pathway in terms of engagement with health and social services, as intervention generally occurs further along the pathway at the court and sentence stages.
- Neighbourhood policing presents a significant opportunity in identifying and supporting people in the community with mental health problems or learning disabilities who may be involved in low-level offending or anti-social behaviour by establishing local contacts and partnerships and developing referral pathways. for the

police to work proactively in local communities with local agencies to help to identify people with mental health problems, in particular, those at risk of offending or re-offending.

- Community support officers and police officers should link with local mental health services to develop joint training packages for mental health awareness.
- To ensure consistency in healthcare provided for individuals in police custody – the NHS and the police should explore the feasibility of transferring commission and budgetary responsibility for healthcare services in police custody suites to the NHS at the earliest opportunity.
- All police custody suites should have access to liaison and diversion services. These services would include improved screening and identification of individuals with mental health problems or learning disabilities, providing information to police and prosecutors to facilitate the earliest possible diversion of offenders with mental disorders from the criminal justice system, and signposting to local health and social care services as appropriate.

Court process

- An audit should be undertaken of the mental health of individuals on remand in approved premises, and the capacity of local services to deal with the identified level of need.
- Training on mental health awareness for all probation and judiciary staff.
- Courts, health services, the Probation service and Crown Prosecution Service should work together to agree a local service level agreement for the provision of psychiatric reports and advice to the courts.
- Liaison and diversion services should form close links with the judiciary to ensure adequate information about the mental health of defendants, and concerning local health services.
- Her Majesty's Courts Service and the Department of Health should investigate how defendants with a dual diagnosis of mental ill health and drugs/alcohol are currently served by all courts, including specialist courts.

Prison, community sentences and resettlement

- A service level agreement between Her Majesty's Courts Service, the Probation Service and the NHS should be developed to ensure the necessary mental health requirements for Community Orders are available.
- The Department of Health and Her Majesty's Courts Service should issue clear guidance for sentencers and probation staff regarding the use of mental health treatment requirements.
- The Department of Health, the NHS and other relevant government departments must work with voluntary organisations to ensure the adequate provision of alcohol

and mental health treatment services across the country.

- An evaluation of the current prison health screen should be undertaken in order to improve the identification of mental health problems at reception into prison.
- Robust models of primary mental health services should be developed, ensuring an appropriately skilled workforce to assess and treat those with mild to moderate conditions and include a range of non-health activities to support well-being in prison.
- The Department of Health should examine the current role of mental health in-reach teams and explore how they can be refocused on providing services for those with severe mental illness. This should include the development of liaison and diversion services to undertake some of the current non-clinical activities.
- NHS commissioners should seek to improve the provision of mental health primary care services in prison.
- The Department of Health should develop a new minimum target for the NHS of 14 days to transfer a prisoner with acute, severe mental illness to an appropriate healthcare setting.
- Improved services for prisoners who have a dual diagnosis of mental health and drug/alcohol problems should be urgently developed.
- An evaluation of treatment options for prisoners with personality disorder should be conducted, including current therapeutic communities in the prison estate.
- The Care Programme Approach has been developed as the fundamental process for ensuring co-ordination and continuity of care for people with mental health problems. To improve continuity of care for prisoners subject to the Care Programme Approach should become a mandatory item in the standard NHS contract for mental health.
- Awareness training on mental health and learning disabilities must be made available for all prison officers. Where appropriate, training should be undertaken jointly with other services to encourage shared understanding and partnership working. Service users should be involved in training development.
- The National Offender Management Service, in partnership with the Department of Health and the NHS, should develop a national strategy for rehabilitation services for those leaving prison with mental health problems who are not subject to supervision from the Probation Service.
- Liaison and diversion services will play a key role in liaising with prison mental health in-reach teams to ensure that planning for continuity of care for prisoners on release is in place. Once a prisoner has been released, the liaison and diversion services will continue to act as a point of information and support for probation and third sector staff and other organisations involved in resettlement.

- Joint care planning between mental health services and drug and alcohol services should take place for prisoners on release.
- A comprehensive mentoring programme for people leaving custody with mental health problems or learning disabilities and returning to the community should be established.

Delivering change through partnership

- National accountability for this agenda will be via a new Programme Board, which will bring together all the relevant government departments, covering health, social care and criminal justice. The National Programme Board will develop a clear, national approach to mental health/learning disability for offenders.
- Development of a national model of Criminal Justice Mental Health Teams with agreed common elements and its roll-out across the country. This will reduce the inconsistency among liaison and diversion schemes. Problems range from differences in the size and workload of schemes, to diverse aims and objectives. A lack of follow-up data on cases makes it difficult to ascertain what the impact of these services has been on mental health outcomes, or on reducing re-offending rates.
- Primary care trusts (PCTs) and partners should jointly plan services for offenders to ensure effective commissioning and delivery of services. Many services that support offenders, for example drug treatment and mental healthcare, are more effectively delivered if partners work together to plan, commission and provide such services. Together, partner organizations must consider the potential for aligning commissioning and pooling of resources to ensure that effective services are available.
- Further research is needed to identify and manage resources effectively. In order to realistically assess what resources might be necessary to support the development of Criminal Justice Mental Health Teams, it is clear that further detailed work will need to be undertaken. The current collection of data is poor in this area in terms of outcomes, and it is difficult to provide evidence on whether such schemes provide value for money.
- Connecting for Health, primary care trusts and strategic health authorities should work together to roll out integrated information systems to health services provided in all criminal justice settings. If stakeholders are expected to improve the way in which information is shared, they must be supported in this by provision of the necessary IT infrastructure. Currently, health information regarding mentally disordered offenders can be accessed locally within the NHS and within prisons, on electronic and/or paper-based records systems. This has a particular impact on the rehabilitation of offenders with mental health problems, as they are routinely difficult to engage with services on release and follow-up is often missed.

Youth offenders^{196 197}

Young people at the boundary between the Criminal Justice System and mental health services are a particularly vulnerable group that face not only the risk of social exclusion but also stigmatisation. However, there is increasing evidence that young offenders are falling between gaps in services. Although there is growing literature on the mental health needs of adolescents in the youth justice system, there remain many unanswered questions surrounding their needs and planning effective interventions.

Young offenders in custody were significantly more likely to have had a previous custodial sentence or community order. The study also found higher rates of young offenders from ethnic minority backgrounds within custody. Many young offenders came from backgrounds where the family structure had broken down, and a history of local authority care placements was common. The links between psychosocial adversity and offending behaviour have already been well established. A history of temporary or permanent school exclusion was also common; learning difficulties has also been associated with many young offenders.

Providing services for this group of young people requires an integrated approach from all the agencies involved in their care, including the Criminal Justice System, social services and mental health services. While 'joined-up working' is essential in providing comprehensive services, there are a number of barriers to this, and services have different aims and different 'languages', which makes this more difficult.

The Youth Justice board¹⁸ commissioned a national study on the mental health needs of young offenders in custody and in the community. The study also looked at models of service provision, and examples of good practice – particularly, what interventions work to reduce mental health needs and offending behaviour.

Findings from this study are outlined below:

Principles of good practice in service provision

- Structured and continuous assessment of the mental health needs of young offenders is required, using reliable and validated tools – e.g. the Mental Health Screening Interview for Adolescents (SIFA) and the Mental Health Screening Questionnaire Interview for Adolescents (SQIFA).
- There needs to be further development of accredited, evidence-based interventions to reduce offending behaviour, with implementation by trained staff.
- There is a need for tailored educational provision based on individual needs and ability (such as learning difficulties).
- Staff working within the secure estate and Youth outreach teams (Yot) require support and supervision, particularly following major incidents.

¹⁹⁶ Prof Richard Harrington, Prof Sue Bailey et al (2005) Mental Health Needs and Effectiveness of Provision for Young Offenders in Custody and in the Community: Youth Justice Board for England and Wales

<http://www.yjb.gov.uk/publications/Resources/Downloads/MentalHealthNeedsfull.pdf>

¹⁹⁷ Children and Young People in the Youth Justice System Report of seminars organised by the All Party Parliamentary Group for Children 2009/10 http://www.ncb.org.uk/media/153014/youth_justice.pdf

- Continuity of care is important, and depends on resources, assessment and the adoption of a (Care Programme Approach) CPA-type model.
- The development of a local multi-agency mental health strategy for both Yots and secure establishments is essential for the delivery of effective interventions. Any strategy should incorporate a multi-disciplinary approach.
- There is a need for clear guidelines regarding confidentiality of records across different professional groups within the youth justice system.

Identification of needs

- Needs for young offenders were often not met, due to a lack of recognition of these needs. This re-enforces the necessity for structured needs and risk assessment procedures. However, this should occur in the context of a mental health screening and training programme within community and secure settings. Within any programme, there should also be clear guidelines for professionals where young offenders screen positive.
- A high proportion of young offenders were identified with low IQs and, critically, almost a quarter had IQs below 70 (the normal range is between 85 and 115). Further research is needed to evaluate the neuropsychological deficits that have been described in these young people and, specifically, whether young offenders have higher rates of learning difficulties, or whether their low IQs are secondary to lack of educational opportunities.
- Continuity of care was variable – supporting the view that there is a need for a CPA that is recognised and accepted by all four key agencies involved (youth justice, mental health, education and social services).

Approaches to address mental health and offending behaviour

- There should be tailored interventions using a cognitive behavioural and problem-solving skills training approach based on assessment of risk, needs and learning abilities.
- There should be a multi-modal approach focusing on the individual, family and peer group.
- Interventions should be evaluated for effectiveness with young offenders and accredited by the Youth Justice Board.
- Those with moderate and severe mental health problems should be identified and referred to the appropriate professional or agency (i.e. CAMHs).
- There should be prioritisation at both national and local level for mental health screening with the development of a local mental health strategy.
- It is essential that all interventions are delivered by fully trained staff.

7. What does the evidence say are effective approaches to tackling loneliness?

In 2011, a study by Masi *et al.* found that Social and economic trends are placing an increasing number of adults at risk for loneliness, an established risk factor for physical and mental illness. It also concluded that this can affect the individual themselves as well as those around them¹⁹⁸. In particular as noted earlier in the overall literature review, mental health of parents or care givers is a risk factor for mental ill health amongst children and young people and so tackling loneliness can benefit more than the individual impacted. In the literature and debates surrounding loneliness there is a focus on older people although loneliness is not only experienced by those who are older¹⁹⁹. However, much of the literature surrounding loneliness is focussed on the older age groups.

Prevalence of loneliness in the UK amongst children and young people is not well understood, an American study estimates that 12% of kindergarten and first graders reported feeling lonely at school²⁰⁰. For older people it is estimated that the proportion of older people feeling lonely often or always is between 6 and 13%²⁰¹.

The effect of loneliness on British Society has been recognised by the Government following evidence about the physical and mental health impacts which include vascular resistance, elevated systolic blood pressure in older adults, less restorative sleep, diminished immunity and links to cognitive decline²⁰². Loneliness increases feelings of threat and vulnerability which is thought to lead to the physiological functioning²⁰³. Personality disorders, psychoses, suicide, impaired cognitive performance and increase in depressive symptoms have been associated with loneliness²⁰⁴. The Department of Health have included a measure in both the Adult Social Care and Public Health Outcomes Frameworks (2013-14) in response to the commitment outlined in the Adult Social Care White paper earlier in 2012 to support people to develop and maintain their social contacts. The outcome objective and measure is as follows:

Outcome Objective: People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation.

¹⁹⁸ Masi, C., et al, 2011. A Meta-Analysis of Interventions to Reduce Loneliness. *Personality and Social Psychology Review*, vol 15, no 3

¹⁹⁹ Victor C., et al, 2005. The prevalence of, and risk factors for, loneliness in later life: a survey of older people in Great Britain" in *Ageing and Society*, vol 25, pp 357-375

²⁰⁰ Masi, C., et al, 2011. A Meta-Analysis of Interventions to Reduce Loneliness. *Personality and Social Psychology Review*, vol 15, no 3

²⁰¹ Local Government Association, 2012, *Combating loneliness: A guide for Local Authorities*, available at: <http://www.campaigntoendloneliness.org.uk/wp-content/uploads/downloads/2012/03/A-guide-for-local-authorities-combating-loneliness.pdf>

²⁰² Masi, C., et al, 2011. A Meta-Analysis of Interventions to Reduce Loneliness. *Personality and Social Psychology Review*, vol 15, no 3

²⁰³ Hawkey, L., et al, 2010. Loneliness Matters: A Theoretical and Empirical Review of Consequences and Mechanisms. *Annals of Behavioural Medicine*, vol 40, no 2, pp 218-227

²⁰⁴ *Ibid*

Measure: Proportion of people who use services and their carers, who reported that they had as much social contact as they would like.²⁰⁵

Nevertheless, the measure included is arguably a measure of social isolation which is why understanding what we mean by different terms is important. Equally, whilst measuring the level of social isolation in the Borough over time will mean we are able to monitor the impact of our interventions, an understanding of the best interventions to tackle loneliness is needed. The rest of this literature seeks to answer such questions.

Definitions

Literature discussing issues around loneliness is careful to denote the difference between loneliness and social isolation which in some social commentary is used interchangeably. Social isolation is an objective measure of social interactions and loneliness is subjective, for example someone can be surrounded by a group of people who are part of their social network but can *feel* lonely or someone can be “socially contented while alone”²⁰⁶. In some discussions around this topic a distinction is made between emotional loneliness and social loneliness:

Emotional loneliness: “the absence of a significant other with whom a close emotional attachment is formed (e.g. a partner or best friend)” (Burholt cited in Age UK Oxfordshire, 2011: 10)

Social loneliness: “the absence of a social network consisting of a wide or broad group of friends, neighbours and colleagues” (Burholt cited in Age UK Oxfordshire, 2011: 10)²⁰⁷

Results

Intervention Strategies

As reported by Masi *et al.* (2011) qualitative reviews have identified 4 primary intervention strategies:

1. Improving social skills;
2. Enhancing social support;
3. Increasing opportunities for social contact; and
4. Addressing maladaptive social cognition²⁰⁸

Length of intervention to target loneliness has been found to need to be at least about two years to have the maximum effect on alleviating depressive symptoms²⁰⁹. However, it is accepted in the sector that the strength of interventions focussed “up-stream” is that they are provided by the Voluntary and Community Sector by volunteers working alongside the

²⁰⁵ Department of Health (2012). The Adult Social Care Outcomes Framework 2013-14, available at: <http://www.dh.gov.uk/health/files/2012/11/The-Adult-Social-Care-Outcomes-Framework-2013-14.pdf>

²⁰⁶ Masi, C., et al, 2011. A Meta-Analysis of Interventions to Reduce Loneliness. *Personality and Social Psychology Review*, vol 15, no 3

²⁰⁷ Age UK Oxfordshire, 2011, *Safeguarding the Convoy: A call to action from the Campaign to end loneliness*

²⁰⁸ Masi, C., et al, 2011. A Meta-Analysis of Interventions to Reduce Loneliness. *Personality and Social Psychology Review*, vol 15, no 3

²⁰⁹ VanderWeele, T., 2011. A marginal structural model analysis for loneliness: implications for intervention trials and clinical practice. *Journal of Consulting and Clinical Psychology*, vol 79 no 2, pp 225-235

community²¹⁰. Whilst there are a number of different intervention strategies which research suggests are effective the lower level support that's available in communities should not be disregarded. The Local Government Association (2012) has produced a guide for Local Authorities entitled "Combating Loneliness" which focuses on older people²¹¹. The guide suggests that combating loneliness requires strategic, neighbourhood and individual intervention. Strategically this involves:

- Building the issues of loneliness into broader strategies with sign up and support from Chief Officers and Councillors based on an understanding of the wider impact on health and wellbeing of loneliness – social prescribing is an intervention that has been cited; and
- Raising awareness of the issue – amongst professionals and the community – examples include Belfast Healthy Ageing Strategic Partnership who have delivered training to health professionals to help them better understand and respond to isolation.

Neighbourhood action is noted as improving place (to mitigate barriers to people accessing their community), maximising community assets and infrastructure and building community capacity through co-production, time banks, community events and empowering community leaders.

Individual actions involve identifying and reaching those in need, understanding risk factors and providing a range of appropriate support for those who are lonely. The risk factors for loneliness are noted as including:

- low socio economic sector;
- being aged 80+;
- living alone;
- having no access to car/never using public transport;
- living in rented accommodation;
- living on low income or on benefits as main income;
- having no access to a telephone; and
- hearing and sight loss²¹²

Understanding the risk factors can help to target and design the interventions but also combined with raising awareness of the issue can help draw people's attention to the issue amongst those they live or work with.

This literature review now reviews evidence related to different interventions structured around the 4 intervention strategies discussed by Masi *et al.* (2011)²¹³.

²¹⁰ Windle et al, 2011, Preventing loneliness and social isolation: interventions and outcomes, available at: <http://www.scie.org.uk/publications/briefings/briefing39/>

²¹¹ Local Government Association, 2012, Combating Loneliness: A guide for Local Authorities, available at: <http://www.campaigntoendloneliness.org.uk/wp-content/uploads/downloads/2012/03/A-guide-for-local-authorities-combating-loneliness.pdf>

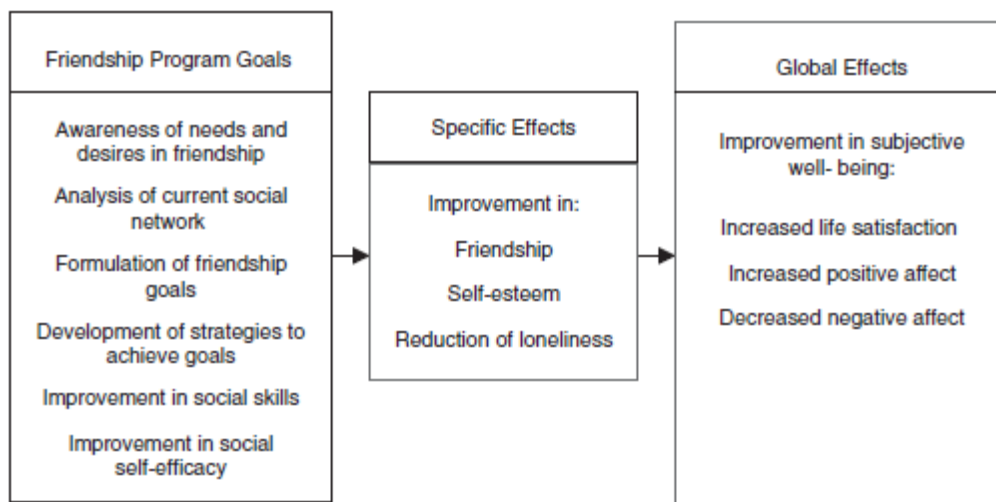
²¹² Ibid

²¹³ Masi, C., et al, 2011. A Meta-Analysis of Interventions to Reduce Loneliness. *Personality and Social Psychology Review*, vol 15, no 3

Improving social skills

A study exploring the effectiveness of friendship enrichment amongst older women found that there was a decline in loneliness following the programme, nevertheless there was also a decline in the control group too.²¹⁴ The model within which the study is based on is illustrated in figure 4. The programme consists of 12 lessons including theory, practice of friendship skills and role playing difficult situations. The theory that the programme is based is that an improvement in friendship will increase the availability of support and companionship in the social networks of the participants, and this should lead to a reduction in loneliness and improvement in subjective wellbeing.²¹⁵

Figure 4. Model for effects of participation in the Friendship Enrichment Programme



Source: Martina and Stevens, 2006: 468

The researchers conclude that such programmes should be part of a wider programme of activities that promote social contact on one hand but includes meaningful ways of spending time alone on the other; hence using a combination of individual and group interventions. They conclude that other personal, situational and contextual factors are important for factors affecting loneliness that more successful programmes would need to consider.

Enhancing social support and increasing opportunities for social contact

There is mixed evidence about the role enhancing social support or increasing opportunities for social contact has on reducing loneliness:

The “small effects of interventions to increase opportunities for social interaction or enhance social support suggest that reducing social isolation does not necessarily reduce loneliness”²¹⁶

The next section of the literature review considers different intervention types within this category and the evidence found as a result of the literature review.

²¹⁴ Martina, C., and Stevens, N., 2006, “Breaking the Cycle of Loneliness? Psychological effects of a friendship enrichment programme for older women” in *Aging and Mental Health*, vol 10, no 2

²¹⁵ Martina, C., and Stevens, N., 2006, “Breaking the Cycle of Loneliness? Psychological effects of a friendship enrichment programme for older women” in *Aging and Mental Health*, vol 10, no 2

²¹⁶ Masi, C., et al, 2011. A Meta-Analysis of Interventions to Reduce Loneliness. *Personality and Social Psychology Review*, vol 15, no 3

Psychosocial Group Intervention

Research conducted by Savikko *et al.* found that psychosocial group intervention had a positive impact on loneliness: “sharing loneliness resulted in feelings of togetherness among participants, as they noticed that others are lonely, too. Sharing experiences and receiving peer support encouraged participants to trust other group members”. (p.22)²¹⁷

The researchers found that from being in a group, doing things together, disclosing experiences and feelings led to peer support. Participants confirmed that their loneliness was alleviated as a consequence of the intervention and that the intervention had socially activated them...Of the participants, 95% felt that their loneliness was alleviated during the intervention.²¹⁸

Pitkala *et al* found that stimulating group intervention improved cognition of older people suffering from loneliness. They found that psychosocial group intervention had promising effects on health, cognition, and psychological well-being of elderly lonely people.²¹⁹

Group based interventions

Nevertheless, Masi *et al.* are more cautious about the success of group based interventions; simply bringing lonely people together may not result in new friendships because the thoughts and behaviours of lonely individuals make them less attractive to one another as relationship partners. Of the meta analysis conducted by Masi *et al* (2011) group based interventions were no more effective than individual based interventions.²²⁰

Research conducted by Cattan *et al* (2005) into a review of health promotion interventions that tackle isolation and loneliness amongst older people reported more positively about group activities. From their work 90% of effective interventions (n=10) were group activities with an educational or support input. 75% of ineffective interventions (n=8) were individual interventions which involved one to one social support, advice and information or health needs assessment. The only common factor of ineffective interventions was that they were one to one interventions conducted in people’s own homes. From their work Cattan *et al* concluded that education and social activity can be effective for alleviating social isolation and loneliness amongst older people. They also suggest that incorporating activities known to enhance self-esteem and personal control may improve the long term effectiveness of group interventions²²¹. Factors including how involved older people are in the planning of activities, development and delivery were seen to impact the effectiveness of reducing isolation and loneliness with effectiveness increasing with level of involvement. Social group activities with a creative, therapeutic or discussion based focus are supported by research –

²¹⁷ Savikko, N., et al, 2010, “Psychosocial group rehabilitation for lonely older people: favourable processes and mediating factors of the intervention leading to alleviated loneliness” in International Journal of Older People Nursing, vol 5 no 1, pp 16-24

²¹⁸ Ibid

²¹⁹ Pitkala, K., 2011. Effects of Socially Stimulating Group Intervention on Lonely, Older People’s Cognition: A Randomized Controlled Trial. The American Journal of Geriatric Psychiatry, vol 19, no 7

²²⁰ Masi, C., et al, 2011. A Meta-Analysis of Interventions to Reduce Loneliness. Personality and Social Psychology Review, vol 15, no 3

²²¹ Cattan, M., White, M., Bond, J. and Learmouth, A. (2005), ‘Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions’, *Ageing and Society*, 25: 41–67.

subjective health and survival results were better for those in the intervention group compared to the control group.²²²

Home visiting and befriending

The evidence for home visiting and be-friending services in reducing loneliness is unclear²²³. From the work conducted by Cattan (2005) despite one-to-one support (befriending, home visiting and carer support) being frequently provided to tackle loneliness and despite older people responding positively to it, current evidence on the effectiveness of one to one interventions is not clear.

Nevertheless, SCIE state that befriending has been shown to reduce loneliness (2012: 3), and that the intervention has a modest but significant effect on depressive symptoms. SCIE presents an economic case supporting befriending services with potential savings potentially outweighing costs. A cost saving of about £300 per year per person has been shown to be achieved from a cost of £80 per person.²²⁴

Community Navigator Services

From work completed for SCIE, Windle et al (2011)²²⁵ conclude that Community Navigator Services which identify those suffering from social isolation are effective. Whilst, as stated earlier in this literature review, social isolation and loneliness are distinct issues and as Masi et al (2011)²²⁶ conclude reducing social isolation does not necessarily reduce loneliness. Nevertheless, for those without opportunity for social contact it's difficult to see that pragmatically such support doesn't go some way to reducing loneliness and therefore such projects may be effective. Community Navigator projects are reported to be projects where volunteers who work with those that are "hard to reach" or are "vulnerable" and provide emotional, practical and social support. They can act as the bridge between the individual and the community and help find suitable interventions within the community that can be accessed. The models for such services vary on local need but can include face to face home visits or telephone contact. The services described in the report seem similar to those provided by the Link Age Plus Outreach Workers who work with those over 50 in Tower Hamlets.

Addressing maladaptive social cognition

Masi *et al*²²⁷ conducted their own meta-analysis of literature relating to loneliness interventions to quantitatively determine whether the outcomes of loneliness interventions varied based on study design, intervention type or other study characteristic. Randomised group comparison studies that addressed maladaptive social cognition had a higher mean effect size than interventions that attempted to improve social skills, enhance social support, or increase opportunities for social interaction. Maladaptive social cognition refers to negative perceptions of yourself and how other people perceive you. The researchers concluded that interventions that use Cognitive Behavioural Therapy and psychological re-

²²² Social Care Institute for Excellence, 2012, Preventing loneliness and social isolation among older people, available at: <http://www.scie.org.uk/publications/atagance/atagance60.asp>

²²³ Cattan, M., White, M., Bond, J. and Learmouth, A. (2005), 'Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions', *Ageing and Society*, 25: 41–67.

²²⁴ Windle et al, 2011, Preventing loneliness and social isolation: interventions and outcomes, available at: <http://www.scie.org.uk/publications/briefings/briefing39/>

²²⁵ Ibid

²²⁶ Masi, C., et al, 2011. A Meta-Analysis of Interventions to Reduce Loneliness. *Personality and Social Psychology Review*, vol 15, no 3

²²⁷ Ibid

framing can in particular reduce loneliness. Of the studies included by Masi *et al*/the four social cognitive training interventions achieved greater loneliness reduction when compared with interventions designed to increase social support, social skills or opportunities for social intervention. Results from Hawkey *et al* (2010)²²⁸ support Masi *et al*'s findings.

The LGA in their toolkit for Local Authorities state "Psychological therapies, such as cognitive behavioural therapy may be effective for older people experiencing chronic loneliness" (p 36). The LGA (2012) have also highlighted however that a lack of access to psychological services for older people has been highlighted as a gap. The Improving Access to Psychological Therapies needs to include the needs of lonely individuals²²⁹.

Use of technology to combat loneliness

A Dutch study has found that an Internet at Home project for chronically ill or disabled older people reduced levels of emotional loneliness when compared to the control group with a significant reduction in feelings of loneliness²³⁰. However, the study was small scale involving 15 people and levels of loneliness reduction were highest amongst those who were more highly educated. Whilst the study provides some evidence that use of the internet to reduce feelings of loneliness the study did not select candidates who had a negative attitude towards computers, therefore highlighting such an approach can support those who are already IT literate but not necessarily not those who are not. Whilst the study focussed on older adults the impact of such intervention on younger aged adults would be interesting – no such study has been found as part of this literature review.

In the UK there are telephone befriending schemes as well as telephone circles in replace of one to one home visits, nevertheless, the evidence is unclear about their effectiveness to reduce loneliness²³¹.

A video-conferencing project in Taiwan working with older residents in nursing homes has been found to reduce residents' perceived loneliness and improved their depressive status at 3, 6, and 12 months after the intervention²³². The video-conferencing used laptops and communication software and older people were supported by a trained research assistant for the first 3 months and for the 9 months following by nursing home staff that were trained. Appointments were organised with friends of family members to interact with the older person over the internet. From this study researchers suggest that videoconference use is a good way to reduce loneliness of the elderly in both the community and institutions²³³.

²²⁸ Hawkey, L., et al, 2010,. Loneliness Matters: A Theoretical and Empirical Review of Consequences and Mechanisms. *Annals of Behavioural Medicine*, vol 40, no 2, pp 218-227

²²⁹ Local Government Association, 2012, *Combating loneliness: A guide for Local Authorities*, available at: <http://www.campaigntoendloneliness.org.uk/wp-content/uploads/downloads/2012/03/A-guide-for-local-authorities-combating-loneliness.pdf>

²³⁰ Fokkema, T., and Kinscheer, K., 2007, "Escape loneliness by going digital: a quantitative and qualitative evaluation of a Dutch experiment using ECT to overcome loneliness among older adults" in *Aging and Mental Health*, vol 11, no 5, pp 496 - 504

²³¹ Age UK Oxfordshire, 2011, *Safeguarding the Convoy: A call to action from the Campaign to end Loneliness*

²³² Kossman, S., 2011. Changes in Depressive Symptoms, Social Support, and Loneliness Over 1 Year After a Minimum 3-Month Videoconference Program for Older Nursing Home Residents. *Journal of Medical Internet Research*, vol 13 no 4

²³³ *Ibid*

Social isolation

The evaluation of the national programme by Link Age Plus, which focused on older people and included research conducted in Tower Hamlets, highlights the importance in reducing social isolation. The evaluation concluded that individual Link Age Plus projects reduced social isolation²³⁴.

8. What are the effective approaches and recommendations for suicide prevention?

Suicide is a major issue for society and a leading cause of years of life lost. Suicide is often the end point of a complex history of risk factors and distressing events; therefore prevention has to address this complexity. Every suicide is a both an individual tragedy and a terrible loss to society. The impact can be devastating; economically, psychologically and spiritually for all those affected.

An inclusive society that avoids the marginalisation of individuals and which supports people at times of personal crisis will help to prevent suicides. Government, statutory and community services have a role to play. This can be done by providing support to vulnerable people in the care of health and social services and at risk of suicide are supported and kept safe from preventable harm or intervening quickly when distress or crisis occurs.

The Preventing suicide in England – A cross-government outcomes strategy to save lives²³⁵ was published on 10th September 2012 by the Department of Health and is intended to provide an approach to suicide prevention that recognises the contributions that can be made across all sectors of our society.

National picture

Suicide rates in England have been at a historical low recently and are low in comparison to those of most other European countries. But still, over 4,200 people took their own life in 2010.

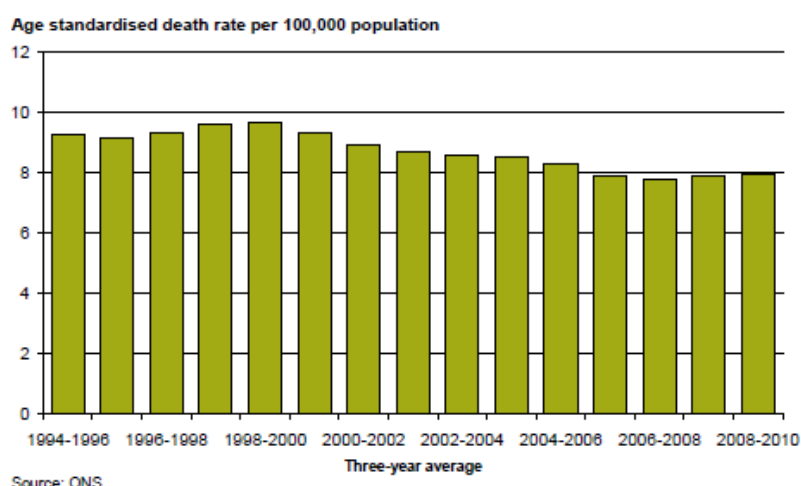
In England in 2008-10, the mortality rate from suicide was 12.2 deaths per 100,000 population for males and 3.7 deaths for females.²³⁶ The latest 15-year trend in the mortality rate from suicide and injury of undetermined intent using three-year pooled rates is shown in Figure 5.

²³⁴ Davis, H., Ritters, K. The LinkAge Plus national evaluation: End of project report. Accessed at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/186772/572summ.pdf. Accessed July 2013.

²³⁵ Preventing suicide in England (2012 DH) <http://www.dh.gov.uk/health/files/2012/09/Preventing-Suicide-in-England-A-cross-government-outcomes-strategy-to-save-lives.pdf>

²³⁶ Office for National Statistics and Department of Health (2010) *DH Mortality Monitoring Bulletin (Life expectancy, all-age-all-cause mortality, and mortality from selected causes, overall and inequalities)*, available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/dH_120638

Figure 5. Death rates from intentional self-harm and injury of undetermined intent, England 1994-2010



Source: Office for National Statistics and Department of Health (2010) *DH Mortality Monitoring Bulletin (Life expectancy, all-age-all-cause mortality, and mortality from selected causes, overall and inequalities)*

The past couple of years have seen a slight increase in suicide rates, but the 2008-10 rate remains one of the lowest rates in recent years. Despite this, we know from experience that suicide rates can be volatile as new risks emerge which demonstrates the need for continuing vigilance and why, despite relatively low rates, a new suicide prevention strategy for England is needed.

High-risk groups and risk factors

It is important to recognise that suicide risk is complex and for many people it is a combination of factors (individual, societal and cultural) that determines risk rather than any single factor which include:

- Gender – males are three times as likely to take their own life as females
- Age – people aged 35-49 now have the highest suicide rate
- Mental illness
- Treatment and care they receive after making a suicide attempt
- Physically disabling or painful illnesses including chronic pain
- Alcohol and drug misuse

Stressful life events can also play a part such as:

- Job loss
- Debt
- Living alone, becoming socially excluded or isolated
- Bereavement
- Family breakdown and conflict including divorce and family mental health problems
- Imprisonment

Stigma, prejudice, harassment and bullying can all contribute to increasing an individual's vulnerability to suicide.

Objectives and areas for action

The Preventing suicide in England strategy sets out two overall objectives²³⁷:

- To reduce the suicide rate in the general population in England; and
- provide better support for those bereaved or affected by suicide.

The six key areas that have been identified for action to support delivery of these objectives are:

1) *Reduce the risk of suicide in key high-risk groups.* Which include:

- Young and middle-aged men
- People in the care of mental health services (including inpatients)
- People with a history of self-harm, people in contact with the criminal justice system
- Specific occupational groups such as doctors, nurses, veterinary workers, farmers and agricultural workers.

Suicide prevention approaches include:

- Accessible, high-quality mental health services for people of all ages with mental health problems.
- Those who work with men in different settings especially primary care, need to be particularly alert to the signs of suicidal behaviour.
- Emergency departments and primary care have important roles in the care of people who self-harm.
- Continuing to improve mental health outcomes for people in contact with the criminal justice system.

2) *Tailor approaches to improve mental health in specific groups.*

Improving the mental health of the population as a whole is another way to reduce suicide this strategy identifies the following groups for whom a tailored approach to their mental health is necessary if their suicide risk is to be reduced:

- Children and young people
- Survivors of abuse or violence, including sexual abuse
- Veterans
- People living with long-term physical health conditions
- People with untreated depression
- People who are especially vulnerable due to social and economic circumstances
- People who misuse drugs or alcohol
- Lesbian, gay, bisexual and transgender people
- Black, Asian and minority ethnic groups and asylum seekers

Suicide prevention approaches include:

- Schools, social care and youth justice system, highlighting problems such as bullying, low body image and lack of self-esteem among children and young people.

²³⁷ Department of Health. Access at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216928/Preventing-Suicide-in-England-A-cross-government-outcomes-strategy-to-save-lives.pdf

- Timely identification and referral of women and children experiencing abuse or violence to access appropriate support.
- The *No health without mental health*²³⁸ strategy made it clear the importance for parity of esteem between mental and physical health. Routine assessment for depression as part of personalised care planning for people with long-term conditions can help reduce inequalities and help people to have a better quality of life.
- As depression is one of the most important risk factors for suicide. A major emphasis should be on the early identification and prompt, effective treatment of depression.
- Given the links between mental ill-health and social factors like unemployment, debt, social isolation, family breakdown and bereavement, the ability of front-line agencies to identify and support (or signpost to support) people who may be at risk of developing mental health problems is important for suicide prevention.
- Alcohol and drug agencies play an important role in reducing substance misuse which is critical in reducing suicide.
- Staff in health and care services, education and the voluntary sector need to be aware of the higher rates of mental distress, substance misuse, suicidal behaviour or ideation and increased risks of self-harm amongst lesbian, gay and bisexual people, as well as transgender people.
- Community initiatives can be effective in bridging the gap between statutory services and Black, Asian and minority ethnic communities, and in tackling inequalities in health and access to services.

3) *Reduce access to the means of suicide.*

One of the most effective ways to prevent suicide is to reduce access to high-lethality means of suicide.

Suicide methods most amenable to intervention are:

- Hanging and strangulation in psychiatric inpatient and criminal justice settings
- Self-poisoning
- Those in high-risk locations
- Those on the rail and underground networks

Suicide prevention approaches include:

- Continued vigilance by mental health service providers will help to identify and remove potential ligature points. Safer cells complement care for at-risk prisoners.
- Safe prescribing can help to restrict access to some toxic drugs.
- Local agencies can prevent loss of life when they work together to discourage suicides at high-risk locations. Local authority planning departments and developers can include suicide in health and safety considerations when designing structures which may offer suicide opportunities.

²³⁸ No health without mental health (2011 DH)
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_124058.pdf

- On-going work is taking place by the British Transport Police, London Underground Limited, Network Rail, Samaritans and partners to reduce suicides on the rail and underground networks.

4) *Provide better information and support to those bereaved or affected by suicide.*

It is important to:

- Provide effective and timely support for families bereaved or affected by suicide which is essential to help the grieving process and support recovery.
- Have in place effective local responses to the aftermath of a suicide.
- Provide information and support for families, friends and colleagues who are concerned about someone who may be at risk of suicide.

5) *Support the media in delivering sensitive approaches to suicide and suicidal behaviour.*

- The media have a significant influence on behaviour and attitudes. They can provide support by:
- Promoting the responsible reporting and portrayal of suicide and suicidal behaviour in the media.
- Continuing to support the internet industry to remove content that encourages suicide and provide ready access to suicide prevention services.

6) *Support research, data collection and monitoring.*

The Department of Health will continue to support high-quality research on suicide, suicide prevention and self-harm through the National Institute for Health Research and the Policy Research Programme. Reliable, timely and accurate suicide statistics are essential to suicide prevention consideration will be given on how to get the most out of existing data sources and options to address the current information gaps around ethnicity and sexual orientation. Reflecting the continuing focus on suicide prevention, the Public Health Outcomes Framework includes the suicide rate as an indicator.

Developments to the coroner system and data collection

• *Support for those bereaved or affected by suicide*

Coroners have an important role in carrying out and certifying an inquest of suspected suicide deaths and will extend its service to be able to help bereaved families to find support from local and national organisations.

• *Reforms to the coroner system*

The Government is reforming the coroner system to include establishing a Chief Coroner who will be responsible for:

- Providing national leadership to coroners in England and Wales.
- Play a key role in setting new national standards and developing a new statutory framework for coroners including rules and regulations, guidance and practice directions within which coroners will operate.

- Coroners will be under a duty to inform the Chief Coroner of any investigations lasting more than a year and the Chief Coroner will be under a duty to include a summary of these in an annual report.

This will help to bring about much greater consistency of practice between coroner areas and improved service to the bereaved, as well as helping to speed up the investigation and inquest process. Build on existing sources of data on suicide and improve the systematic collection of and access to data on suicides.

- *Data collection*

Currently, the information in the national mortality statistics produced by ONS is useful for identifying national trends, but does not allow more detailed analysis. Preventative interventions and monitoring would be enhanced if more comprehensive information was more easily accessible - additional information may be held in coroners' records and records from GPs or secondary care and mental health services, but it is not routinely or systematically reported. At a local level, coroners may work with health services and partner organisations and agencies to provide data that will give an early indication of emerging patterns, such as clusters or particular patterns of suicides, before data are compiled by the ONS.

Making it happen

Cross-cutting outcomes strategies recognise that the Government can achieve more in partnership with others than it can alone, and that services can achieve more through integrated working than they can through working in isolation from one another. This new approach builds on existing joint working across central government departments, and between the Government, local government, local organisations, employers, service users and professional groups, by unlocking the creativity and innovation.

It is important to recognise that the *Preventing Suicide in England* strategy sits alongside the government's mental health strategy *No health without mental health* which outlines the proposed reforms to the public health, health and social care systems and how the new vision will affect planning and delivery of improved health outcomes many of which have direct relevance to suicide prevention. The first agreed objective of *No health without mental health* aims to ensure that more people will have good mental health. To achieve this there is the need to:

- Improve the mental wellbeing of individuals, families and the population in general.
- Ensure that fewer people of all ages and backgrounds develop mental health problems.
- Continue to work to reduce the national suicide rate.²³⁹

No health without mental health includes new measures to develop individual resilience from birth through the life course, and build population resilience and social connectedness within communities. These too are powerful suicide prevention measures.

²³⁹ No health without mental health: implementation framework (DH 2012)
<http://www.dh.gov.uk/health/files/2012/07/No-Health-Without-Mental-Health-Implementation-Framework-Report-accessible-version.pdf>

The Government is supporting the national mental health Time to Change programme which aims to address stigma and discrimination which can act as a barrier to people seeking and accessing the help that they need, increasing isolation and suicide risk.

Suicide prevention is also explicitly covered in the *No health without mental health*²⁴⁰ strategy implementation framework and is an indicator within the Public Health Outcomes Framework which will help to track national progress.

From April 2013, Public Health England will support local areas to help improve outcomes in public health and reduce health inequalities, including on mental health and suicide prevention. This will depend on partnerships across health, social care, education, the environment, housing, employment, the police and criminal justice system, transport and the voluntary sector.

In addition to this, new health and wellbeing boards (HWBs) will also be able to support suicide prevention as they bring together local councillors, Clinical Commissioning Groups, directors of public health, adult social services and children's services, local Healthwatch and others. HWBs will assess the local community's health and wellbeing needs aimed at making improvements in population health and wellbeing, including mental health, which will reduce the risks of suicide.

It is clear that a key enabler towards achieving the objectives of the *Preventing suicide in England* strategy includes a co-ordinated multi-sector approach to deliver interventions that address a range of risk factors for suicide. It is equally important to note that work in this area is reinforced by other national strategies such as the *No health without mental health* strategy.²⁴¹

On-going work and research on preventing suicide in England

The Department of Health, through the National Institute for Health Research (NIHR) and the Policy Research Programme (PRP), has invested significantly in mental health research and will continue to support high-quality research on suicide, suicide prevention and self-harm. The Department of Health will work with the National Suicide Prevention Strategy Advisory Group to consider how we can get the most out of the existing data sources in England and address the issues around collecting data more routinely and systematically. This will include considering options to address the current information gaps around ethnicity and sexual orientation.

The Department of Health will also work with the Ministry of Justice and coroners to consider what access to coroners' records may be achievable for bona fide researchers, subject to relevant data protection and confidentiality safeguards and bearing in mind coroners' statutory duties.

The varying detail given by coroners in narrative verdicts means that, in some cases, ONS find it difficult to classify intent accurately – which can impact on the reliability of local figures²⁴². In light of this, ONS made changes to the processing of narrative verdicts for all

²⁴⁰ Ibid

²⁴¹ No health without mental health: implementation framework (DH 2012)
<http://www.dh.gov.uk/health/files/2012/07/No-Health-Without-Mental-Health-Implementation-Framework-Report-accessible-version.pdf>

²⁴² Office for National Statistics and Department of Health (2010) *DH Mortality Monitoring Bulletin (Life expectancy, all-age-all-cause mortality, and mortality from selected causes, overall and inequalities)*

deaths registered from 2011 onwards. (It is important to note that the national monitoring statistics depend on the data generated by the coroners' reporting system so it will be important to bear in mind the continuity of data and information when making these changes). The Public Health Outcomes Framework now includes the suicide rate as an indicator. Two other indicators with direct relevance to suicide prevention are self-harm and excess under 75 mortality in adults with serious mental illness.

Conclusions/Recommendations

A study by the National Research Council and the Institute of Medicine reviewed the research on the prevention of mental disorders and substance abuse among young people and recommended multiple strategies for enhancing the psychological and emotional well-being of young people²⁴³. In general, the conclusions of that work are in line with those made in this literature review. To introduce those findings the key themes are that the following elements should be part of a programme of mental health promotion amongst children and young people:

- *Strengthening families* by targeting problems such as substance use or aggressive behaviour; teaching effective parenting skills; improving communication; and helping families deal with disruptions (such as divorce) or adversities (such as parental mental illness or poverty).
- *Strengthening individuals* by building resilience and skills and improving cognitive processes and behaviours.
- *Preventing specific disorders*, such as anxiety or depression, by screening individuals at risk and offering cognitive training or other preventive interventions.
- *Promoting mental health in schools* by offering support to children encountering serious stresses.
- *Promoting mental health through health care and community programmes* by promoting and supporting pro-social behaviour, teaching coping skills, and targeting modifiable life-style factors that can affect behaviour and emotional health, such as sleep, diet, activity and physical fitness, sunshine and light, and television viewing.

EIP services offer an evidence-based outcome approach to supporting people with first time psychosis. Findings suggest²⁴⁴:

- The early phase is critical and requires a specialist intensive recovery focus intervention.
- Reducing the duration of untreated psychosis can improve life chances.
- High service user and carer satisfaction.
- Compelling evidence of the clinical and cost effectiveness of EIP over standard care.
- Positive indicators for long-term savings.
- Cost savings can be quantified within the health sector as well as across wider society.
- Regardless of the long-term savings, the benefits of early savings are not lost.
- Opportunities to support delivery of key objectives within the Mental Health Strategy.

²⁴³ The National Academy of Sciences, 2009

²⁴⁴ Mental Health Network NHS Confederation May 2011 Briefing: Early intervention in psychosis services, Issue 219.

Future needs of early Intervention

There are areas that still need to be addressed with regard to early intervention. The two main domains are those of relapse²⁴⁵ and even though many patients make good symptomatic recoveries functional recovery has lagged behind²⁴⁶. It is recognised that a number of these young people will remain needy, vulnerable and with persistent symptoms/distress beyond the current tenure of a typical EIP service model (internationally between 1.5-3 years).

Further research is also needed in the effectiveness of early intervention in the preonset phase and criteria for identification of those at risk of psychosis. This area has received a number of criticisms which include people being mislabelled, potentially stigmatized and exposed to treatment that they did not need because they were not going to develop psychosis('false positives').

It is the view that an early intervention in psychosis service should be seen as a beginning of mental health service transformation and not an endpoint. Therefore, a continuum of care is needed to ensure that people with first episode psychosis make sustained recoveries that give them every opportunity to participate fully in life.

Overall, further work is needed to explore and identify the effective approaches to improve the experience of people with mental health problems in primary care services. Based on the existing research the following elements have been identified as core components that can lead to improved satisfaction and experience of people with mental health problems in primary care:

- Improve understanding of mental health of health care professionals to reduce stigma and preconceptions related to this group.
- Improve communication skills of health care professionals to better understand the patient's needs, build trust and deliver a more continuous and holistic (physical, social and mental) approach to care.
- Train health care professionals on mental health services to support a more seamless referral pathway.
- Mental health support groups – to identify barriers, share learning and deliver education sessions for staff and patients.
- Adopt approaches that are culturally sensitive and accessible.
- Evaluate effectiveness of approaches with health care professionals and patients for on-going service improvement.

Substance abuse

Conclusions from the substance abuse research show that this abuse is a common and devastating co-existing disorder among persons with severe mental illness. Recent research offers evidence that integrated dual diagnosis treatments are effective, however interventions are rarely incorporated into the mental health programs in which these clients receive care. Successful implementation of dual diagnosis services within mental health systems will depend on changes at several levels: clear policy directives with consistent organizational and financing supports, programme changes to incorporate the aim of addressing co-occurring substance misuse and mental illness, support for the acquisition of

²⁴⁵ Gleeson J. (2005) Preventing EPISODE II: relapse prevention in first-episode psychosis. *Australasian Psychiatry* 13;384-387.

²⁴⁶ Killackey E., et al (2006) Exciting Career Opportunity Beckons! Early Intervention and Vocational Rehabilitation in First Episode Psychosis: Employing Cautious Optimism. *Aust N Z J Psychiatry*; 40:951-962.

expertise at the health and social care levels and availability of accurate information to clients and family members.

In regard to the criminal justice system, the literature clearly outlines the importance of an integrated service model between the criminal justice system, diversion & liaison, health service, social care and other agencies is at the heart of supporting people with a mental health problem who are in the criminal justice system. The first step to the effective management of offenders is the existence of good early identification and assessment of problems to inform how and where they can be most appropriately treated, highlighting diversity and the range of needs that exist among these individuals (including young offenders). However, crucial to this is the establishment of governance arrangements at a national, regional and local level to set this work in progress. These arrangements will also feed into consistency in delivery across the country and improved data collection for measuring progress and effectiveness of service delivery.

STIGMA AND DISCRIMINATION: A REVIEW OF THE LITERATURE

Scope

This paper reports the findings of a review conducted to answer the question:

1. What are the practically focussed interventions that the partnership can take to reduce stigma and discrimination?

Introduction

The Governments *No Health Without Mental Health Strategy*²⁴⁷ as well as other national research papers (The Foresight Report namely) highlight tackling stigma and discrimination as an important issue for national and local action. The impact of stigma and discrimination on people with mental health problems is big, it can affect people accessing help and support, it can keep people isolated, stop people working and can limit people's expectations.

In defining stigma researchers have viewed it as an overarching term which consists of three elements²⁴⁸:

- The problem of knowledge - Ignorance
- The problem of attitudes - Prejudice
- The problem of behaviour – Discrimination²⁴⁹

Stigma has been shown to operate at three different levels:

- Public stigma – where large social groups endorse stereotypes about mental illness
- Self-stigma – where people internalise public stigma, which results in a loss of self-esteem and self-efficacy.
- Label avoidance – where people avoid seeking help and thus being labelled with a stigmatising mental health problem.²⁵⁰

Essentially the aim is for Tower Hamlets to be a community that is aware of mental health issues, has an understanding and treats people with mental health problems (and their carers and families) as any other member of the community i.e. addressing knowledge, attitudes and behaviour. The working theory is that as public understanding of mental health improves, negative attitudes and behaviours to people with mental health problems will decrease.

Time to Change conducted a survey to find out how stigma affects those living with mental health problems²⁵¹. The results of the national survey are clear; 9 out of 10 service users (87%) reported the negative impact that stigma and discrimination had had on their lives. The results show that actual and feared stigma and discrimination stopped people with mental health problems doing things as part of everyday life including participating in employment, education, going on holiday and reporting a crime (Time to Change, 2008). The

²⁴⁷https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/135457/dh_124058.pdf. Accessed June 2013.

²⁴⁸ Thornicroft et al., 2008, "Reducing stigma and discrimination: candidate interventions" in *International Journal of Mental Health Systems*, 2 (3), pp 110-117

²⁴⁹ Young Minds. <http://www.youngminds.org.uk/assets/0000/1324/stigma-review.pdf>. Accessed June 2013.

²⁵⁰ Ibid

²⁵¹ Time to Change. <http://www.time-to-change.org.uk/files/Stigma%20Shout.pdf>. Accessed June 2013.

findings from the survey showed that proportions stating the impact on their lives were higher for women, people with severe mental illness, the LGBT community, those with other disabilities and those who were middle aged clearly an important consideration for any partnership intervention.

National policy is clear that mental health is everyone's business and it's everyone's responsibility to challenge stigma and discrimination – what does this mean and what are the practically focussed effective interventions that the partnership can take to reduce stigma and discrimination?

Methods

This review of the literature involved using nationally recognised agencies tackling stigma and discrimination like Time to Change and Young Minds as the first contact point for research on successful interventions. From this initial scan further research from other sources and institutions was found.

Findings

Cross Cutting

“Stigma is a prejudice (negative attitude) based on stereotypes usually leading to discrimination.” (Byrne, P., 2009)²⁵².

Discrimination can be experienced at an individual level, institutional level or at a structural level. Stigma is a high priority issue for those with current and those with previous mental health problems, it's “cited above poverty, isolation and homelessness as a main source of social exclusion”²⁵³.

Higher risk and marginalised groups are more likely to suffer stigma and discrimination including looked after children, the homeless, those who are or have been in prison, BME groups, those with learning disabilities and those who've experienced abuse²⁵⁴. As from the statistics noted earlier²⁵⁵ and from the graphs below, fear of stigma as well as actual stigma is a factor in affecting people's lives. For people with mental health problems and their carers it's therefore important that they feel confident that stigma and discrimination is being tackled in the community. Figures 1 and 2 below depict the survey results and show that carer reported stigma and discrimination is lower than that reported by those with mental health problems themselves although still high, disclosure amongst carers was significantly the highest anticipated stigma.

²⁵² Byrne, P., 2009, “Stigma in 100 words” in *The British Journal of Psychiatry*, 195: 80, available at: <http://bjp.rcpsych.org/content/195/1/80.short>

²⁵³ Royal College of Psychiatrists, 2010, *No Health without Public Mental Health: the Case for Action*

²⁵⁴ Ibid

²⁵⁵ Time to Change. <http://www.time-to-change.org.uk/files/Stigma%20Shout.pdf>. Accessed June 2013.

Figure one: What service users stop or fear doing because of stigma and discrimination.

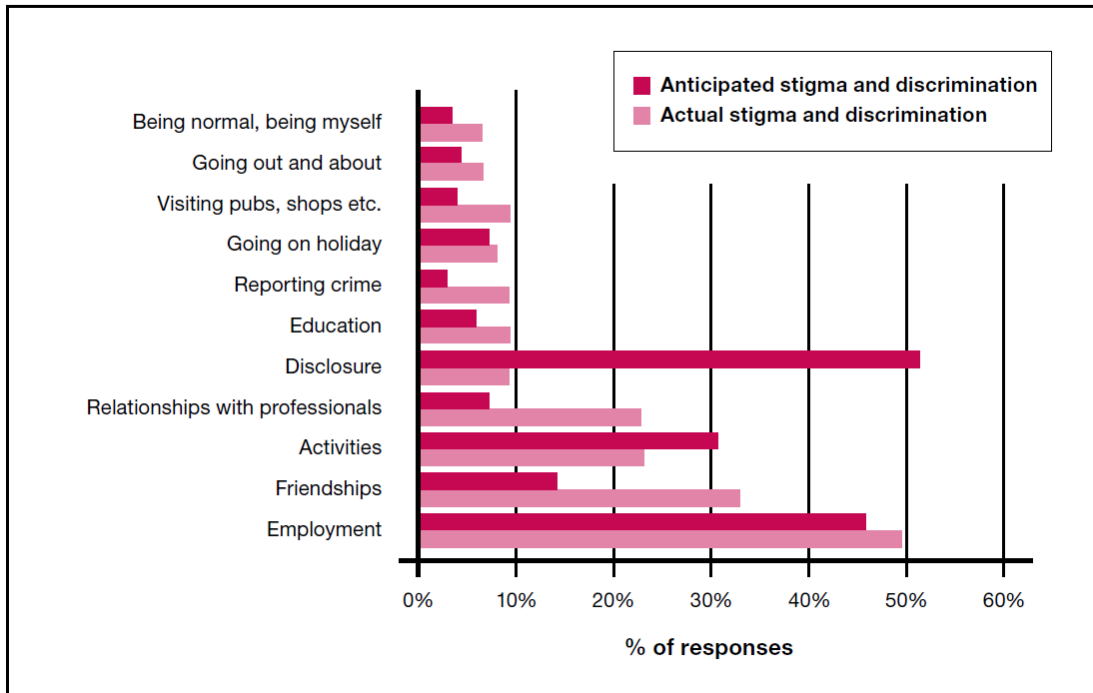
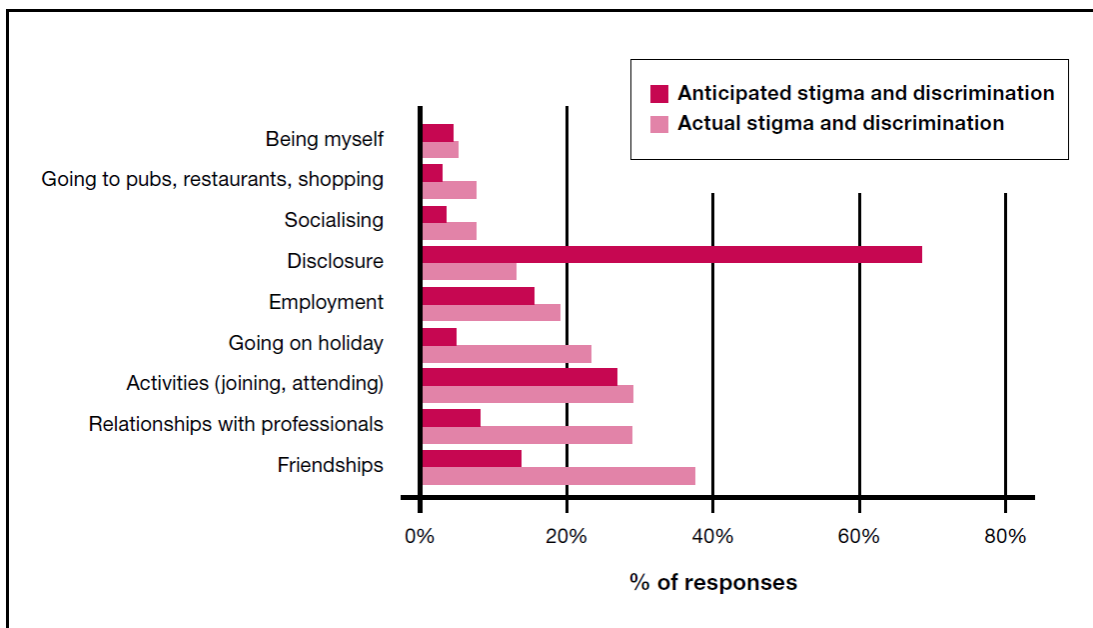


Figure two: What carers stop or fear doing because of stigma and discrimination.



Education about mental health is a common theme in attempts to tackle stigma related to mental health. Although, whilst raising knowledge about the subject, education does not, in itself, change attitudes. Thornicroft *et al.*²⁵⁶ have suggested that tackling stigma and discrimination programmes cannot rely solely on education programmes for a long lasting

²⁵⁶ Thornicroft et al., 2008, “Reducing stigma and discrimination: candidate interventions” in International Journal of Mental Health Systems, 2 (3), pp 110-117

impact. Corrigan *et al.* (2005)²⁵⁷ suggests that successfully tackling stigma needs to combine:

1. Campaigning;
2. Education and
3. Giving people *contact* with a lived experience of mental health problems.

Taking a *whole system approach* to tackling stigma is also advocated at individual, service, organisational level and including the media and members of the community. All parts of the system have their role to play. For a local mental health strategy however it's important to consider what can and should be done locally against those activities that need to be driven nationally. The No Health without Mental Health Strategy and the Time to Change campaign mean that nationally there's support for addressing and tackling stigma and discrimination and locally we need to identify what else that should be done to make sure we maximise the opportunity locally.

Work from Time To Change highlights a number of factors that should be considered when working to tackle mental health stigma and discrimination, these are:

- *Sustaining focus*: tackling stigma and discrimination is a long term objective and any approach needs to be sustainable and continued. In this sense the mental health and wellbeing strategy needs to identify actions for the short, medium and long term.
- *Multi-layered*: a programme of activity to tackle stigma and discrimination needs to include messages about challenging myths about mental health, it needs to share positive messages, share local experience and incentivise behaviour change (organisationally, organisationally and in the community).
- *Direct Involvement*: involve those that have experienced stigma and discrimination as a result of their own mental health in planning, delivering and evaluating the anti-stigma campaign/approach.

In addition, the Foresight "Mental Capital and Wellbeing Project" highlights that as well as being sustained, an approach to tackling stigma and discrimination needs to include a range of stakeholders, examples given are family, employers, schools and media – acknowledging that sites of stigma and discrimination vary throughout the lifecourse²⁵⁸.

From the survey conducted by Time to Change²⁵⁹ the top 5 institutions that an anti-stigma and discrimination campaign should be targeted at were media, schools, NHS mental health services, large corporate organisations and GPs. Important messages for ant stigma campaigns were:

- We are people – see me, not the illness (service user 51%, carer 44%);
- Having a mental health problem is a common part of life 1 in 4 (service user 42%, carer 45%);

²⁵⁷ Corrigan et al., 2005, "The stigma of mental illness: explanatory models and methods for change" in Applied and Preventive Psychology, vol 11

²⁵⁸ Foresight, 2008, Mental Capacity and Wellbeing Project

²⁵⁹ Time to Change, 2008, Stigma Shout: The Service User and Carer Experiences of Stigma and Discrimination

- People with mental health problems can and do recover to lead rewarding and fulfilling lives (service user 37%, carer 35%); and
- We should have the same rights as everyone (service user 37%, carer 33%).

However, put into a Tower Hamlets context a focus on cultural and religious factors is important and hence working with religious leaders and institutions in Tower Hamlets should be part of any approach to tackle stigma and discrimination. Research conducted by Time to Change²⁶⁰ about attitudes to mental health in a South Asian Community in Harrow gives a number of important insights for consideration in Tower Hamlets:

- *Normalise* mental health problems, tackling mental health as a taboo subject encouraging individuals and communities to talk about the issues around mental health problems;
- *Tackle misunderstandings* about the causes of mental health problems; and
- *Raising awareness* of mental illness in the community to help people identify the signs and seek help early.

Being Born

Stigma related to post natal depression can be a barrier to new mums admitting the need for help and accessing it²⁶¹, these issues are complex and can be bound up both in terms of stigma related to mental health but also perceptions about what a good or bad mother is.

Possible interventions:

- Media campaigns targeting myths and social constructs about parenting and the challenges that new families face.
- Reinforcing emotional and mental health support services as part of the normal perinatal journey.²⁶²

Growing Up

Research cited in the National CAMHS Support Service Tackling Stigma: A Practical Toolkit by Dr Warner-Gale²⁶³ suggests that to tackle mental health stigma amongst children, young people and their families 8 domains need to be implemented together to achieve maximum effect, these are:

- *Mainstreaming* involves gaining commitment from professionals, embedding tackling stigma in policies, procedures, policies and action plans.
- *Language and Definition* develop agreed age appropriate definitions of mental health to facilitate discussion about what mental health is and the support that's available for children, young people and families. Findings from local research with young people in Tower Hamlets endorse shared language and definition. In terms of recognising mental health problems the research concludes that "there was a lot of confusion

²⁶⁰ Time to Change, 2012, Family Matters: A report into attitudes towards mental health problems in the South Asian community in Harrow, North West London

²⁶¹ Bilszta, J., Erikson, J., and Milgrom, J., 2010, "Women's experience of postnatal depression – beliefs and attitudes as barriers to care", Australian Journal of Advanced Nursing, Vol 27 No 3, Available at: http://www.ajan.com.au/Vol27/AJAN_27-3.pdf#page=45

²⁶² Ibid

²⁶³ NCSS, Tackling Stigma: A Practical Toolkit. <http://www.chimat.org.uk/tacklingstigma>. Accessed June 2013.

around what was meant by the term mental health” (Millbank Social Marketing, 2012: 38).

- *Information* develop and disseminate age appropriate information about child mental health including how to access services, what to expect from support services, what happens next, etc.
- *Education* training available for the children’s workforce about what stigma is and its impact, particularly how it can affect seeking help and appropriate treatment, development of training to be co-produced with children and young people with mental health problems and their families
- *Communication* keep children, young people and their families informed and involved in care and treatment
- *Effective systems* clear, well communicated care pathways and referral criteria. Service delivery integrated into mainstream settings if possible to normalise accessing emotional wellbeing and mental health services.
- *Media as allies* work with local media to provide accurate information about mental health, raise awareness of the impact of stigma and negative stereotypes, disseminate information about the support available locally and to tell positive local stories.
- *Citizenship and participation* involvement of children, young people and their families.

Research conducted by the Time to Change programme highlighted schools as an important institution to target anti-stigma mental health campaigns. The rationale is to ensure that the new/younger generations understand and develop attitudes which challenge stigma and discrimination in order to break the cycle. The No Health Without Mental Health Strategy indicates that the role of schools in tackling stigma and discrimination should be about addressing bullying, training for school staff and challenging mental health stigma.²⁶⁴

Local work to understand local knowledge and attitudes of young people about mental health has recommended rolling out an educational programme in Tower Hamlets Secondary Schools. The recommendations suggest that an interactive session promoting positive messages such as “you can recover and achieve what you want in life, instead of stigma” including information about symptoms, where to go for health and preventative measures should be rolled out²⁶⁵. However, before this is done the report highlights the importance of liaising with the school’s Personal, Social, Health and Economic teachers to secure support for such a programme and careful consideration of who would be best placed to deliver such a programme. The options included are:

- Develop bespoke training for teachers;
- Commission training to nationally recognised organisation; or
- Work with a local community group to identify those recovered from mental health problems to go and speak in schools about their experiences (Millbank Social Marketing, 2012)

²⁶⁴ DH, 2012, No Health Without Mental Health: Implementation Framework

²⁶⁵ Millbank Social Marketing, 2012, Determining the attitudes of young people towards mental health and their responses to challenging stigmatising perspectives – A service improvement project

Being an adult

As the Time to Change survey results show, employment is an area where a high level of stigma is experienced by people with mental health problems (just under 50% of respondents to the survey said that they had stopped employment as a result of actual stigma and discrimination in the work place)²⁶⁶.

Thornicroft *et al* (2008)²⁶⁷ highlight a number of actions for local communities of health and social care economies including:

- Provide supported work schemes for people with mental health problems working with local employers;
- Provide psychological treatments to improve cognition, self-esteem and confidence of people with mental health problems returning to work;
- Health and Social Care employers to give credit to applicants with a history of mental illness when recruiting staff; and
- Work with local employers to provide reasonable adjustments at work for people with mental health problems.

As local leaders in Tower Hamlets the Council and the NHS arguably have a role in “leading by example” with regards to this. The Mayor signing the Time to Change Pledge and the Health and Wellbeing Board encouraging all Board members to sign is the start of this. Providing support for people with mental health problems to flourish in the work place could include the following practical interventions, which all arguably require strong HR support (both in terms of advice and policies and procedures that are supportive and flexible) for managers:

- Working with employees to identify what makes the work environment easier for them to manage e.g. having a quieter work place with fewer distractions for people with concentration problems, allowing the use of headphones, giving clear assignments;
- Having more frequent 1:1s and giving regular feedback and guidance on performance at work;
- Flexible working hours so appointments can be kept or when affected by medication leaving early or coming in late can be enabled;
- Opportunities for external job coaches, counselling support, mentor scheme, etc.²⁶⁸

Growing older

For those who are growing older with mental health problems stigma can be two fold, that related to older age and that related to mental health problems²⁶⁹. An effective intervention for reducing stigma in Asian communities was “brief exposure to information about the symptoms of dementia, in the form of vignettes about people with the illness”. For dementia, the recommendations for reducing stigma and discrimination are in-line with those at other stages of the lifecourse including, educating the public, reducing isolation, giving a voice to

²⁶⁶ Time to Change, 2008, Stigma Shout: The Service User and Carer Experiences of Stigma and Discrimination

²⁶⁷ Thornicroft *et al.*, 2008, “Reducing stigma and discrimination: candidate interventions” in *International Journal of Mental Health Systems*, 2 (3), pp 110-117

²⁶⁸ *Ibid*

²⁶⁹ Alzheimer’s Disease International, 2012, World Alzheimer Report 2012: Overcoming the Stigma of Dementia

those with dementia, recognising the rights of those with dementia and their carers, involving people with dementia in their communities and improving dementia awareness training amongst health and social care staff²⁷⁰.

Conclusions/Recommendations

Thornicroft *et al* (2008)²⁷¹ conclude that:

“The strongest evidence for effective interventions at present is for (i) direct social contact with people with mental illness at the individual level, and (ii) social marketing at the population level”.

Based on this and the broader evidence results discussed above it is recommended that the Borough:

- Explore co-producing a local anti-stigma campaign (not necessarily labelled as such and using the Time to Change pledge) with people who have experienced stigma and discrimination as a result of their mental health, including children, young people and their families, delivered through a range of settings and channels.
- Establish an umbrella campaign with specific focus elements including specific focus on BME communities and religious networks, those with disabilities, those with severe mental illness, the LGBT community and middle aged to older people. Identifying local people who are prepared to share their experiences at talks, in case studies, etc. would be beneficial to maximise people’s contact with real experience.
- Progress with the education programme outlined for secondary schools.

²⁷⁰ Ibid

²⁷¹ Thornicroft *et al.*, 2008, “Reducing stigma and discrimination: candidate interventions”. *International Journal of Mental Health Systems*, 2 (3), pp 110-117

SUPPORTING FAMILIES: A REVIEW OF THE LITERATURE

Scope

The literature review aimed to answer the following questions:

1. What are the most effective interventions to promote positive outcomes for children who have a parent with a mental illness?
2. What does the evidence say to support the effectiveness, including cost-effectiveness, or otherwise, of interventions aimed at the family as the unit of intervention, as opposed to the individual with a mental health problem?
3. What should the NHS be doing in order to support emotional resilience in children and young people?

As a comprehensive review was done recently in regard to carers, this review focuses on family members. It was not possible to conduct a systematic review due to the time constraints, therefore the quality of the studies was not assessed and no meta-analysis was conducted. However, a systematic search was performed using the well-established databases, such as EMBASE and MEDLINE.

Introduction

Good mental health is important for a stable, secure and thriving society. There is evidence that mental and emotional wellbeing underpins successful learning and enables children and young to realise their potential – positive emotions are recognised to enhance learning²⁷². Despite its importance, one in ten children and young people (10 percent) aged 5-16 have a clinically diagnosed mental disorder²⁷³.

One of the most potent risk factors for adolescent depression is being the child of a parent who has mental health problems²⁷⁴. Parental mental illness has extensive consequences on family life and on offspring social adjustment and mental health in childhood and in later life, depression and anxiety being the major mental health problems^{275 276}. Children of depressed parents are about four times more likely to develop a mood disorder than those of non-depressed parents²⁷⁷.

The intergenerational transfer of psychiatric disorders and the increasing prevalence of common mental health conditions²⁷⁸, create an urgent need to develop interventions to support families where there are parental mental health problems^{279 280}. Several preventive

²⁷² Young Minds. Building Emotional Resilience in Denny Schools (BERDS): A Pilot Intervention. Evaluation Report. January 2009

²⁷³ ONS. Mental health of children and young people in Great Britain, 2004. Accessed November 2012:

http://www.ic.nhs.uk/webfiles/publications/mentalhealth04/MentalHealthChildrenYoungPeopleSummary310805_PDF.pdf

²⁷⁴ Institute of Medicine (1994). *Reducing risks for mental disorders: Frontiers for preventive intervention research*.

Washington, DC: National Academy Press

²⁷⁵ Beardslee WR, Versage EM, Gladstone TRG (1998) Children of affectively ill parents: a review of the past 10 years. *J Am Acad Child Adolesc Psychiatry* 37:1134–1141

²⁷⁶ Weissman MM, Wickramaratne P, Nomura Y, Warner V, Pilowsky D, Verdelli H (2006) Offspring of depressed parents: 20 years later. *Am J Psychiatry* 163:1001–1008

²⁷⁷ Beardslee, W. R. (1998). Prevention and the clinical encounter. *American Journal of Orthopsychiatry*, 68, 521-533.

²⁷⁸ Murray CJL, Lopez AD (eds) (1996) *The global burden of disease*. Harvard University Press on behalf of the World Health Organization, Cambridge

²⁷⁹ Mrazek PJ, Haggerty RJ (eds) (1994) *Reducing risks for mental disorders: frontiers for preventive intervention research*. National Academy Press, Institute of Medicine, Washington

²⁸⁰ National Research Council, Institute of Medicine (2009) *Preventing mental, emotional, and behavioral disorders among young people: progress and possibilities*. Committee on Prevention of Mental Disorders and Substance Abuse Among Children, Youth, and Young Adults: Research Advances and Promising Interventions. The National Academies Press, Washington, DC

interventions for children with family adversity have been developed and found to be efficacious in randomised controlled trials. Details of these interventions are presented in this review.

Methods

Studies meeting the following criteria were included in the review:

- a. *Publication type*: Due to time limitations, where possible, only systematic reviews were searched for. However, if the reviews identified were regarded as dated or had a poor search strategy, the following publication types were included: randomised controlled trials, non randomised control trials, non-systematic reviews, comparative studies, qualitative studies, case reports and presentations from experts²⁸¹.
- b. *Participants*: Male and female adults and children, no age restrictions applied.
- c. *Language and country or origin*: Where there was a strong body of evidence from the UK, this was focused upon. Only where there was limited UK evidence, did the search include studies focused on interventions in other countries, such as the USA. Only studies written in English were included.

Search strategy:

A systematic search was conducted using of six electronic databases to identify relevant studies on recovery from mental illness – PubMed, Web of Science, CINAHL, EMBASE, PsycINFO and the Cochrane Library. We searched for papers published in English between 1992 and 2012 using the keywords and combinations of keywords set out under each of the key questions below. The reference lists of all included studies were reviewed to identify additional articles. In addition, a search engine was used to identify any relevant reports and research studies conducted by relevant third sector organisations and government departments.

The MEDLINE search was conducted on PubMed using MeSH search terms, such as mental disorders [MeSH].exp OR mental OR psychiatr* AND adolescent psychology*. The search terms were adapted for the other databases.

Findings

1. What are the most effective interventions to promote positive outcomes for children who have a parent with a mental illness?

Interventions developed in Europe, North America and Australia were identified through the search and collated into two main categories: (i) cognitive therapy/counselling, and (ii) peer-support programmes.

²⁸¹ The order of study prioritisation was based on Hierarchy of evidence used by the Cochrane collaboration.

(i) *Cognitive therapy/counselling*

Several preventive interventions for children who have a family member with a mental health problem (most frequently a parent with unipolar depression) have been found to be efficacious in randomised controlled trials. These interventions have used a range of therapy techniques, such as cognitive restructuring therapy and family counselling.

One of the trials, conducted in Finland²⁸² aimed to study the effectiveness of two interventions: a more extensive Family Talk Intervention (FTI)²⁸³ and a short child-focused Let's Talk about Children discussion (LT). Both interventions were coupled with a guide book for parents. Both interventions prevented the rise in children's symptoms, as well as leading to a decrease in these symptoms. As the study team were able to control for the parents' depression, these positive changes were not due to alleviation of parental depression, which is known to be associated with symptom reduction in children²⁸⁴. The study also found that the children's prosocial behaviour improved and emotional symptoms, anxiety, and marginally, hyperactivity decreased both in the FTI and the LT, while the FTI was more effective in reducing emotional symptoms relative to the LT. The higher effectiveness of FTI was time dependent. It is noteworthy that the positive changes in the FTI tend to happen during the first 4 months. LT took longer to have an impact.

Two randomised trials^{285 286} evaluated the effectiveness of two standardised manual-based prevention strategies for families with parental mood disorder. The trials demonstrated that brief, family-centered preventive interventions for parental depression may contribute to long-term, sustained improvements in family functioning. The trials tested two interventions: two informational lectures, and a brief clinician-based approach (M = 7 sessions) including child assessment and a family meeting. In the 2007 trial, child and parent family functioning²⁸⁷, increased for both intervention groups, and internalising symptoms as measured on the Youth Self Report decreased for both groups. However, in the earlier trial, whilst children reported increased understanding of parental illness attributable to participation in the interventions, and understanding of parental illness improved there was no significant effect of group on children's change in internalising symptomatology.

Cognitive restructuring therapy was trialled with the teenage children of adults treated for depression²⁸⁸. The teenagers were randomised to usual care or usual care plus a 15-session group cognitive therapy prevention programme. The enhanced intervention reduced the risk of depression in the children. A group cognitive behavioural prevention programme also had a significant prevention effect based on both clinical diagnoses and self-reported

²⁸² Solantaus T, Paavonen J, Toikka S, Punamäke R. Preventive interventions in families with parental depression: children's psychosocial symptoms and prosocial behaviour. *Eur Child Adolesc Psychiatry* (2010) 19:883–892

²⁸³ Beardslee WR, Wright E, Rothberg PC, Salt P, Versage E (1996). Response of families to two preventive intervention strategies: long-term differences in behavior and attitude change. *J Am Acad Child Adolesc Psychiatry* 35:774–782. FTI is designed to enhance family communication and understanding concerning depression and to support interpersonal relationships in the family and children's social life outside the family, which have all been documented to build up family and child strengths and resilience.

²⁸⁴ Gunlicks ML, Weissman MM (2008) Change in child psychopathology with improvement in parental depression: a systematic review. *J Am Acad Child Adolesc Psychiatry* 47:379–389

²⁸⁵ Beardslee WR, Wright EJ, Gladstone TR, Forbes P (2007) Longterm effects from a randomized trial of two public health preventive interventions for parental depression. *J Fam Psychol* 21:703–713

²⁸⁶ Beardslee WR, Gladstone TR, Wright EJ, Cooper AB (2003) A family-based approach to the prevention of depressive symptoms in children at risk: evidence of parental and child change. *Pediatrics* 112:e119–e131

²⁸⁷ As measured by the Family Relations Inventory

²⁸⁸ Clarke GN, Hornbrook M, Lynch F, Polen M, Gale J, Beardslee W, O'Connor E, Seeley J (2001) A randomized trial of a group cognitive intervention for preventing depression in adolescent offspring of depressed parents. *Arch Gen Psychiatry* 58:1127–1134

depressive symptoms. However, this effect was not evident for adolescents with a currently depressed parent²⁸⁹.

(ii) *Peer support*

In addition to the RCTs detailed above which focus on cognitive/counselling interventions, a number of studies assessed the impact of peer support programmes. The programmes were offered as school holiday programmes, after-school programmes, or camps, targeted at 7–18 years, and aimed to increase children's knowledge about mental illness, develop peer relationships and enhance children's adaptive coping skills.

A peer support intervention piloted in the UK, found that participants valued project workers and group work²⁹⁰. The project, aimed at 11–16 year olds caring for a parent with a mental illness, provided the young people with respite and support. However, the sample was small (n=10) and the evaluation was qualitative in nature.

Another seven peer support programmes were identified, where a more thorough evaluation had been conducted, two using a RCT design. Of the seven studies, four were conducted in Australia, and the remaining three in North America.

Both of the RCTs reported positive results, including: higher levels of self-esteem and diminished use of maladaptive coping strategies²⁹¹; increased mental health literacy, pro-social behaviour and life satisfaction, and decreased depression and emotional symptoms²⁹². The other five studies which measured outcomes pre and post reported positive results, in relation to improvements in self-esteem²⁹³, reduction in depressive symptoms²⁹⁴, and increased knowledge and coping skills.^{295 296 297}

A recent review of peer support interventions identified some potential risks, such as exposing children to unsettling information about mental illness and limiting peer-support networks to those in the programmes²⁹⁸. The review also concluded that long-term outcomes remain unclear due to the lack of longitudinal data.

There was also some literature around bibliotherapy. Bibliotherapy presents children with literature involving characters who are in similar positions to themselves. This is done in an attempt to help children normalise their situation, gain insight into the problem-solving

²⁸⁹ Garber J, Clarke GN, Weersing VR, Beardslee WR, Brent DA, Gladstone TRG, Debar LL, Lynch FL, D'Angelo E, Hollon SD, Shamseddeen W, Iyengar S (2009) Prevention of depression in at-risk adolescents. a randomized controlled trial. *JAMA* 301:2215–2224

²⁹⁰ Grant G, Repper J, Nolan M. Young people supporting parents with mental health problems: experiences of assessment and support. *Health Soc Care Community* 2008; 16: 271–281.

²⁹¹ Richter GA. Fostering resilience: evaluating the effectiveness of Kids in Control [MA thesis]. Langley, BC: Trinity Western University, 2006.

²⁹² Morson S, Best D, de Bondt N, et al. The Koping Program: a decade's commitment to enhancing service capacity for children of parents with a mental illness. *Adv Ment Health* 2009; 8: 296–295.

²⁹³ Goodyear M, Cuff R, Maybery D, Reupert A. CHAMPS: A peer support program for children of parents with a mental illness. *Adv Ment Health* 2009; 8: 296–304.

²⁹⁴ Hargreaves J, O'Brien M, Bond L, et al. Paying Attention to Self (PATS): an evaluation of the PATS program for young people who have a parent with a mental illness. Melbourne: Centre for Adolescent Health, 2005. Accessed November 2012 http://www.rch.org.au/emplibrary/pats/PATS_FinalEvaluationReport_Dec2005.pdf

²⁹⁵ Orel NA, Groves PA, Shannon L. Positive Connections: a programme for children who have a parent with a mental illness. *Child Fam Soc Work* 2003; 8: 113–122.

²⁹⁶ Pitman E, Matthey S. The SMILES program: a group program for children with mentally ill parents or siblings. *Am J Orthopsychiatry* 2004; 74: 383–388.

²⁹⁷ Riebschleger J, Tableman B, Rudder D, et al. Early outcomes of a pilot psychoeducation group intervention for children of a parent with a psychiatric illness. *Psychiatr Rehabil J* 2009; 33: 133–141.

²⁹⁸ Reupert A, Cuff R, Drost L, Foster K, Doesum K, Santvoort F. Intervention programs for children whose parents have a mental illness: a review. *MJA Open* 2012; 1 Suppl 1: 18–22.

techniques of those characters, and apply this learning to their own lives. However, a recent review concluded that there was no evidence for the efficacy of bibliotherapy in children affected by parental mental illness²⁹⁹.

2. What does the evidence say to support the effectiveness, including cost-effectiveness, or otherwise, of interventions aimed at the family as the unit of intervention, as opposed to the individual with a mental health problem?

Another way of classifying services is according to whether they are provided for individuals (parent or child) or the whole family. In order to evaluate the two approaches, comparisons between family intervention programmes and individual programmes (focusing on the child) need to be made.

Due to time constraints, this question was interpreted in relation to question one - focused on children who have a family member with mental health problems and looking how to prevent them from becoming ill themselves. This review did not look at interventions for children who were already ill, although there is much literature available around this, detailing a range of interventions from music therapy to psychoeducation. Also, the review did not include other family interventions to support adults who have mental health problems. Again, there is a large body of evidence on this topic and therefore it should be viewed as a separate review.

(i) Family-intervention programmes

In an international comparison of child welfare agencies, the development of a 'whole family' approach was identified as one of the main factors associated with good outcomes for families where there are issues with parental mental health³⁰⁰. This approach was supported by the findings detailed in question one. A number of family-intervention programmes were identified and results from these family based programmes provided support for a family-based approach. The majority of these programmes targeted families where a parent has depression and/or anxiety. To summarise the findings from question one, FT targets families where a parent is diagnosed with a major depressive disorder or bipolar disorder, with children aged between 8 and 15 years who have never been treated for an affective disorder. FT uses cognitive techniques directed to parents, children and then some to the family as a whole³⁰¹.

A review of family-based services in children's health and mental health research since 1980 also concluded that there were unequivocal improvements in outcomes including retention in services, knowledge about mental health issues, self-efficacy and improved family interaction when a whole family approach was taken³⁰².

Other studies have found demand for a family approach among patients and their family members. Psychiatric patients were found to want family focused interventions, rather than focusing solely on themselves as the identified parent³⁰³. Similarly, from conducting interviews with parents with mental health issues, their partners, children and support workers, Davis *et al.*, recommended a whole-family intervention³⁰⁴.

²⁹⁹ Reupert A, Cuff R, Drost L, Foster K, Doesum K, Santvoort F. Intervention programs for children whose parents have a mental illness: a review. *MJA Open* 2012; 1 Suppl 1: 18-22.

³⁰⁰ Hetherington, R., Baistow, K., Katz, I., Mesie, J. & Trowell, J. (2002). *The Welfare of children with mentally ill parents: learning from inter-country comparisons*. New York: John Wiley & Sons.

³⁰¹ Huntsman L. Parents with mental health issues: Consequences for children and effectiveness of interventions designed to assist children and their families. November 2008. NSW Department of Community Services.

³⁰² Hoagwood, K. E. (2005). Family-based services in children's mental health: a research review and synthesis. *Journal of Child Psychology and Psychiatry*, 46, 690-713.

³⁰³ Wang, A.-R., & Goldschmidt, V. V. (1996). Interviews with psychiatric inpatients about professional intervention with regard to their children. *Acta Psychiatry Scandinavia*, 93, 57-61.

Despite the positive responses to family based interventions, it has been highlighted that few interventions really include the whole family. In a study by Aldridge, they found that most of the interventions focus on mothers, and often excluded fathers³⁰⁵. By way of contrast, there is little information on the role of fathers in relation to the promotion of resilience in children. Logan *et al.* (2007) noted the lack of research data concerning fathers' attitudes and behaviours³⁰⁶.

Yet the presence of a healthy partner may moderate risk to children, such that Maybery *et al.* (2005) classify children in two parent families as being at significantly lower level of risk than those who are living with a single parent³⁰⁷. Problem behaviours in children of parents with a mental illness where there is minimal marital discord have been shown to be equivalent to children whose parents do not have a mental illness³⁰⁸. Therefore, in such cases, interventions may not be needed, or spousal engagement in interventions may increase their effectiveness³⁰⁹.

Despite the supporting evidence for family based interventions, several longitudinal studies have suggested that resilient children obtain a great deal of emotional support from outside their own family, and they tend to rely on friends, neighbours, and teachers for counsel and comfort in times of transition or crisis³¹⁰. This would suggest that looking at developing interventions outside of the family unit could be effective.

(ii) Individual programmes

Apart from the peer support programmes detailed in question one, individual interventions for children who have a parent with a mental illness typically focused on alleviating caring responsibilities by the child for an ill parent and were usually focused on older children (teenagers). Often the studies also had a parent module as well³¹¹, thereby being classified as a family intervention, or were not preventative studies (there were many interventions for those children already with mental health problems, often caused by parental illness)³¹².

Due to this lack of evidence, it is not possible to determine where interventions aimed at the family as the unit of intervention are more effective than those aimed at the individual. However, when developing any preventative intervention for children of parents with a mental illness, it is important to consider the following, which were identified when the children were asked what they need most:

- more information about their parent's illness;

³⁰⁴ Davis, L., Dibsall, L. & Woodcock, C. (1997). *The Building Blocks Project: investigating the needs of parents and children where a parent has a mental health drug or alcohol problem*, Bromley Children's Project Education Department.

³⁰⁵ Aldridge, J. (2006). The experiences of children living with and caring for parents with mental illness. *Child Abuse Review*, 15, 79-88.

³⁰⁶ Logan, C., Moore, K., Manlove, J., Mincieli, L. & Cottingham, S. (2007). Conceptualising a 'Strong Start': Antecedents of positive child outcomes at birth and into early childhood, *Child Trends Research Brief*, 2007-10, www.childtrends.org

³⁰⁷ Maybery, D., Reupert, A., Patrick, K., Goodyear, M. & Crase, L. (2005). *VicHealth Research Report on Children at risk in families affected by parental mental illness*, Victorian Health Promotion Foundation Mental Health and Wellbeing Unit.

³⁰⁸ Emery, R., Weintraub, S. & Neale, J. (1982). Effects of marital discord on the school behaviour of children of schizophrenic, affective disordered, and normal parents. *Journal of Abnormal Child Psychology*, 16, 215-225.

³⁰⁹ Huntsman L. Parents with mental health issues: Consequences for children and effectiveness of interventions designed to assist children and their families. November 2008. NSW Department of Community Services.

³¹⁰ Werner EE. (1990). Protective factors and individual resilience. Handbook of early childhood intervention. Accessed November 2012: <http://www.healthychild.ucla.edu/wp/pdf/Session2Chapter6ProtectiveFactorsIndividualResilience.pdf>

³¹¹ Essau CA, Conradt J. *Freunde: Prävention von Angst und Depression*. München: Reinhardt; 2003.

³¹² Siegenthaler E, Munder T, Egger M. Effect of preventive interventions in mentally ill parents on the mental health of the offspring: systematic review and meta-analysis. *J Am Acad Child Adolesc Psychiatry* 2012; 51: 8-17.

- to be informed and consulted by professionals who often focus exclusively on the parent's needs;
- someone to talk to; and
- help with practical issues around parent hospitalisation and respite.³¹³

(iii) *Cost-effectiveness*

Improvements in clinical, social and family functioning would be expected to reduce the need for intensive medical and social care and thereby produce economic benefits for service providers. However, where calculations had been attempted these were either unsophisticated assessments of costs or focused primarily on family interventions to support patient relapse, as opposed to protecting 'at risk' family members. Therefore, no robust conclusions could be drawn.

3. What should the NHS be doing in order to support emotional resilience in children and young people?

We conducted a search for what actions the NHS can take to support the emotional resilience in children and young people who have family members with mental illness (following on from question one). There were other papers looking more generally at emotional support to young people who had no family members with a mental illness. However a review of all the evidence was not possible within the scope of this paper. We therefore sought out recent papers that focused on those young people who are at risk due to family illness.

Lessons from best practice

Useful lessons of relevance to the NHS can be drawn from two national programmes, one in Finland and one in Australia.

Finland

The Effective Child and Family Programme (ECFP) was launched in 2001³¹⁴. The aim of the programme is to make a system change in health and social services so that professionals can attend to the needs of adult patients and their children. Under Finnish health and child welfare law, services for adult patients must also attend to the needs of their children. This applies to mental and physical health and substance use services, social services including income-benefit services, and the criminal justice system. As many parents with mental or other illnesses have not sought treatment, the programme is also active with children in schools.

It is mainstream practice now in most Finnish psychiatric services to discuss children and parenting with the patient. Some of the success factors for the ECFP include: (i) the programme is situated in an organisation that has national responsibility; (ii) work started at multiple levels simultaneously (national and community levels, decision-makers and grass root practitioners, families, mass media); (iii) the initial training was extensive and provided expert practitioners and trainers across the country; (iv) a family of methods was developed to be used in different services and by those with different professional orientations; (v) the methods include a low-threshold option (Let's Talk About Children), which does not depart in

³¹³ Siegenthaler E, Munder T, Egger M. Effect of preventive interventions in mentally ill parents on the mental health of the offspring: systematic review and meta-analysis. *J Am Acad Child Adolesc Psychiatry* 2012; 51: 8-17.

³¹⁴ Toikka S, Solantaus T. The Effective Family Programme II: clinicians' experiences of training in promotive and preventative child mental health methods. *Int J Ment Health Prom* 2006; 8: 4-10.

format from traditional patient–clinician sessions; and (vi) research on the two core methods was carried out producing an evidence base for the work³¹⁵.

Australia

The Children of Parents with a Mental Illness (COPMI) national initiative has developed resources to improve support for families where a parent has depression. The Family Focus intervention — based on the Family Talk Intervention includes a DVD for families and an online workforce education resource that provides training for mental health professionals.

Primary care settings have been identified as potential facilitators of the Family Focus DVD and intervention, due to the availability of existing services and pathways for the treatment of depression. Similarly, the current focus on the provision of time-limited, evidence-based interventions in general practice, and the collaborative networks established as part of primary mental health and national health reforms, highlight the significant role of primary care in promoting the mental health of children of parents with depression³¹⁶.

(i) Using primary care

Most parents who are seeking help for common mental conditions, such as depression, will present in primary care. Key factors for GPs are (i) recognising mental illness; (ii) helping parents obtain treatment; (iii) understanding children's concerns and developmental needs; (iv) offering psychoeducation; (v) providing parental guidance; and (vi) follow-up.

Primary care professionals are in an excellent position to provide long-term follow-up and ask periodically about the children of parents. The Beardslee³¹⁷ and Compas³¹⁸ projects provided long-term follow-up, and the benefits of these interventions were revealed over time.

(ii) Recommendations made by other organisations

A number of recommendations were made for commissioners of mental health and Children's services by the Social Care Institute for Excellence³¹⁹. These include:

- *Signposting and improving access to services:* Organisations should develop a multi-agency communications strategy to tackle the stigma and fears that parents and children have about approaching and receiving services.
- *Screening:* Ensure screening and referral systems and practice routinely and reliably identify and record information about which adults with mental health problems are parents, or live with children, and which children have parents with mental health problems. This means developing systems and tools in collaboration with parents and young people, to ensure the right questions are asked and the data is recorded for future use.
- *Assessment:* All organisations need to adapt existing assessment and recording processes to take account of the whole family and train staff in their use. This means

³¹⁵ Solantaus T, Puras D. Caring for children of parents with mental health problems — a venture into the historical and cultural processes in Europe. *Int J Ment Health Prom* 2010; 12: 27-36.

³¹⁶ Parslow RA, Lewis V, Marsh G. The general practitioner's role in providing mental health services to Australians, 1997 and 2007: findings from the national surveys of mental health and wellbeing. *Med J Aust* 2011; 195: 205-209.

³¹⁷ Beardslee WR, Wright EJ, Gladstone TR, Forbes P. Long-term effects from a randomized trial of two public health preventive interventions for parental depression. *J Fam Psychol* 2009; 21: 703-713.

³¹⁸ Compas BE, Forehand R, Thigpen JC, et al. Family group cognitivebehavioral preventive intervention for families of depressed parents: 18- and 24-month outcomes. *J Consult Clin Psychol* 2011; 79: 488-499

³¹⁹ Social Care Institute for Excellence. Think child, think parent, think family: a guide to parental mental health and child welfare. Families' and children's services guide 30. December 2011

developing and implementing 'family' threshold criteria for access to services to take into account the individual and combined needs of parents, carers and children. Strategies for the management of joint cases should be recorded where the situation is complex or there is a high risk of poor outcomes for children and parents.

- *Planning care*: Care planning needs to be flexible enough to meet the needs of each individual family member as well as the family as a whole, and staff should aim to increase resilience and reduce stressors. Allocating an individual budget could provide this flexibility. Increasing every family member's understanding of a parent's mental health problem can strengthen their ability to cope.
- *Providing care*: Commissioners and providers of care should ensure that they can meet the full spectrum of needs, including the practical priorities of parents with mental health problems and their children. This means developing non-traditional and creative ways of delivering services as a way of targeting families and improving access.
- *Reviewing care plans*: Reviews should consider changes in family circumstances over time, include both individual and family goals, and involve children and carers in the process.
- *Taking a strategic approach*: Multi-agency, senior-level commitment is required.

The importance of taking a cross-sectoral and multi-agency approach was also recognised as being important in a qualitative study of young carers in Ireland³²⁰. The report argued that while no individual Government department, agency or service provider has overall responsibility for young carers, there are many different organisations that could potentially support this group of children and young people. Therefore, adopting a cross-sectoral approach was needed. The report also concluded that much can be learnt from the research by Roche and Tucker (2003)³²¹ in the UK focused on ME, which shows that services rarely responded to the child or young person's needs as a carer and instead usually only intervened when there was a child protection concern.

When intervening in schools, a study conducted by Young Minds, concluded that there was a need for further staff training in the area of resilience and emotional wellbeing, and that this was viewed by most Head Teachers as being a priority. However, this study focused on all pupils, as opposed to those who have a family member affected by mental health problems³²².

Conclusions/Recommendations

- Research pointing to the positive aspects of a family-centred approach to family support poses another challenge. Since social isolation or lack of support so often accompanies and exacerbates parental mental illness and problems, building up and strengthening family and other forms of support where these exist would seem to be an important strategy.
- Given the evidence that combining different types of intervention, for example child care and parent education achieves more positive results than a single intervention on its own, more flexibility in combining and adapting programs is now considered both desirable and achievable. Programmes or strategies that involve both parents, where this is possible and extended family members and/or friends to the extent that

³²⁰ Office of the Minister for Children and Youth Affairs. Study of Young Carers in the Irish Population. May 2010. Accessed November 2012:
http://www.childandfamilyresearch.ie/sites/www.childandfamilyresearch.ie/files/study_of_young_carersexecutivesummary.pdf

³²¹ Roche, J. and Tucker, S. (2003) 'Extending the Social Exclusion Debate: An exploration of the family lives of young carers and young people with ME', *Childhood*, Vol. 10, No. 4, pp. 439-56.

³²² Young Minds. Building Emotional Resilience in Denny Schools (BERDS): A Pilot Intervention. Evaluation Report. January 2009

this is appropriate, might start to shift the focus from the individual parent (most often the mother).

- As for child-focused programs, most of those noted above are for older children. It is also worth noting that some professionals argue against interventions directed primarily at children as they fear this labels the child as *the problem* and enables parents to avoid acknowledging their difficulties³²³. But the advantages of quality child care, both as respite for parents and for a richer set of experiences for children of parents who have mental health issues and are socially isolated, seem to be well established.
- There a number of well established factors which can impact on children's emotional resilience, and mental health problems within the family is just one of them. Influencing factors may include: having boy/girlfriend problems; bereavement; not having someone close to talk to; reaction to trauma or abuse; exams/school work; and peer pressure, and so on. It has been argued that a range of factors need to be woven into a proper assessment of the child or young person's circumstances and asked about, as opposed to simply focusing on a single factor, such as having a family member with mental health problems³²⁴.
- Services need the capacity to support and augment families' informal care structures, and consideration as to the role of the father should be harnessed.
- Systematic approaches, such as those used in Finland and Australia, offer the best opportunity for large-scale impact, and there are important strategies that practitioners can employ directly with families.
- More evaluation is required to specifically examine the comparative efficacy of different approaches, to determine what interventions work, for whom, and how and the cost-effectiveness of the interventions.

³²³ Hetherington, R., Baistow, K., Katz, I., Mesie, J. & Trowell, J. (2002). *The Welfare of children with mentally ill parents: learning from inter-country comparisons*. New York: John Wiley & Sons.

³²⁴ NHS Tayside. Supporting Children and Young People at Risk of Self Harm and Suicide: Tayside Multi-Agency Guidance. November 2010. Accessed November 2012: <http://www.nhstayside.scot.nhs.uk/Suicide/Suicide%20-%20final%20copy.pdf>

CRISIS PATHWAYS: A REVIEW OF THE LITERATURE

Scope

This paper reports the findings of a review conducted to answer the following questions:

1. What does the evidence say are the most effective practically focussed interventions that (a) clinical service providers and (b) commissioners can take to manage demand for in-patient admission effectively?

It was not possible to conduct a systematic review due to the time constraints, therefore the quality of the studies was not assessed and no meta-analysis was conducted. However, a systematic search was performed by the East London & The City Alliance Health Intelligence Unit. The search used well-established databases, such as the **British Nursing Index** and MEDLINE. A search of the COCHRANE database was also conducted.

Introduction

Crisis and acute mental health services are a crucial part of mental healthcare, providing for people when they are most unwell and vulnerable³²⁵. The NHS London Health Programmes stated that:

“Good practice for the models of care crisis pathway refers to collaboration between agencies and services, statutory and non-statutory, working together to find more effective ways of meeting the needs of those in mental health crisis based on the principle of right place, right time, right person, right assessment, first time³²⁶.”

Severe psychiatric illnesses are phasic. After initial treatment, those affected by these conditions usually experience long periods of relative stability³²⁷. Relapses can, however, occur for reasons such as exposure to environmental stressors or difficulties with medication concordance. Intervention at this stage is crucial as it brings much needed relief for both the sufferer and their carers and can help prevent further deterioration³²⁸.

A particularly difficult challenge for community treatment of people with serious mental illnesses is the delivery of an acceptable level of care during the acute phases of severe mental illness. Crisis intervention models of care were developed as a possible solution³²⁹.

³²⁵ MIND (2011). Listening to experience – an independent inquiry into acute and crisis mental health care. Accessed November 2012: http://www.mind.org.uk/assets/0001/5921/Listening_to_experience_web.pdf

³²⁶ NHS London Health Programmes (August 2012). London Mental Health Models of Care (Crisis): Policy, guidance and protocols to improve mental health crisis pathway. Accessed November 2012: <http://www.londonhp.nhs.uk/wp-content/uploads/2012/10/12-08-21-Guidance-protocols-mental-health-crisis-pathways-models-of-care-legacy-final.pdf>

³²⁷ Bleuler MJN. The long-term course of the schizophrenic psychoses. *Psychological Medicine* 1974;**4**:244-54.

³²⁸ Weisman GK. Crisis Intervention. In: Bellack AS editor(s). *A clinical guide for the treatment of schizophrenia*. New York: Plenum Press, 1989:101-34.

³²⁹ Joy CB, Adams CE, Rice K. Crisis intervention for people with severe mental illnesses. *Cochrane Database Syst Rev*. 2006 Oct 18;(4):CD001087.

Methods

Search strategy:

Studies meeting the following criteria were included in the review:

- a. *Length of time:* The search included studies from the past 10 years only (2002-2012).
- b. *Language:* Only studies written in English were included.

A systematic search was conducted was performed by the East London & The City Alliance Health Intelligence Unit. The search used seven electronic databases to identify relevant studies, including EMBASE, PsychINFO, CINAHL, **British Nursing Index**, HMIC, COCHRANE and MEDLINE.

The search was conducted using the following search terms:

- I. Crisis OR "Crisis pathway" OR mental illness AND
- II. "pathway"

The potential for emergency residential accommodation outside the hospital setting, commonly referred to as 'crisis housing', to relieve bed pressure on acute wards was identified ten years ago³³⁰. However, this review does not include crisis housing as there is a separate review focussed on crisis housing already completed.

Findings

What does the evidence say are the most effective practically focussed interventions that (a) clinical service providers and (b) commissioners can take to manage demand for in-patient admission effectively?

To try and answer this question, a number of interventions were identified from the identified literature. The evidence available looks at the following intervention types:

1. Home treatment
2. Helplines
3. Consumer providers
4. Community Mental Health Centers
5. Advanced Treatment Directive

Home treatment

Crisis Resolution Home Treatment (CRHT) teams help people through short-term mental health crises by providing intensive treatment and support outside hospital, ideally at home. They are made up chiefly of mental health nurses, with additional input from consultant psychiatrists, social workers, occupational therapists and psychologists.

The National Audit Office (NAO)³³¹ reported that the introduction of CRHT teams has been "*associated with reduced pressure on beds, and the teams are successfully reaching service users who would otherwise probably have needed admission*". In the NAO review, they also

³³⁰ Sainsbury Centre for Mental Health. Acute Problems: A Survey of the Quality of Care in Acute Psychiatric Wards. *The Sainsbury Centre*, 1998

³³¹ National Audit Office. Helping people through mental health crisis: The role of Crisis Resolution and Home Treatment services. Report by the comptroller and auditor general, hc 5 session 2007-2008, 7 December 2007

concluded that CRHT teams were supporting the earlier discharge of people from inpatient treatment – in around 40 per cent of the discharges in their sample. Despite the positive outcomes reported, concern was expressed that CRHT staff head-count was below what it should be. However, this was not the case for London.

The positive findings from the NAO report were supported by another two studies. One of the studies, conducted in Leeds³³², collected data for 2 years prior and 1 year post-implementation of the home-base treatment intervention. The study found that in everyday clinical practice crisis resolution and home treatment teams led to a sustained reduction in in-patient admission rates. A RCT conducted by Johnson *et al.* also reported reduced hospital admissions³³³. A systematic review³³⁴ which looked at all crisis interventions, some of which included home treatment, found that crisis intervention appears to reduce repeat admissions to hospital, particularly so for mobile crisis teams supporting patients in their own homes. Crisis intervention also reduced family burden, and was a more satisfactory form of care for both patients and families.

A recent article which reviewed the effectiveness of crisis resolution home treatment, stressed the importance of gatekeeping, fidelity to the crisis resolution team role without distraction, and of multidisciplinary working. The review also stated that the clients' needs should be at the centre of service delivery, and the team should ensure that referral for home treatment or inpatient admission or discharge is appropriate³³⁵.

Despite the positive outcomes in reduction of hospital admissions and the recent Cochrane review concluding that crisis intervention reduced family burden³³⁶, a qualitative study warned of the impact on the children when a parent is treated at home³³⁷. The study found that whilst home treatment met the patients' needs, the children may be exposed to additional risks and currently lack appropriate support. Therefore the study concluded that the needs of children should be considered in the planning of home treatment for psychiatric crises. In the London based study, home treatment provided good patient care, but most participants felt that they struggled to parent adequately and meet their children's needs. Common difficulties included meeting the children's physical needs, feeling emotionally distant, being dependent on children during the crisis, and struggling to protect the children from exposure to symptoms or distress. Most mothers preferred home treatment to hospital admission, because they felt safer and better looked after at home. However, most children preferred parental hospital admission. Also fears of losing custody was commonly mentioned

³³² Jethwa, Krishma; Galappathie, Nuwan; Hewson, Paul. Effects of a crisis resolution and home treatment team on inpatient admissions. *Psychiatric Bulletin*, May 2007, vol./is. 31/5(170-172).

³³³ Johnson, Sonia; Nolan, Fiona; Pilling, Stephen; Sandor, Andrew; Hoult, John; McKenzie, Nigel; White, Ian R; Thompson, Marie; Bebbington, Paul. Randomised controlled trial of acute mental health care by a crisis resolution team: The north Islington crisis study. *British Medical Journal*, September 2005, vol./is. 331/7517(599).

³³⁴ Murphy S; Irving CB; Adams CE; Driver R. Crisis intervention for people with severe mental illnesses. *Cochrane Database of Systematic Reviews*, 01 May 2012, vol./is. /5.

³³⁵ Hunt, Scott. The effectiveness of crisis resolution home treatment. *Mental Health Practice*, 01 July 2012, vol./is. 15/10(26-28).

³³⁶ Ibid

³³⁷ Khalifeh H; Murgatroyd C; Freeman M; Johnson S; Killaspy H Home treatment as an alternative to hospital admission for mothers in a mental health crisis: a qualitative study. *Psychiatric Services*, May 2009, vol./is. 60/5(634-9), 1075-2730;1557-9700 (2009 May)

by the mothers, and this in turn could prevent help-seeking behaviour. Ostman and Hansson (2002) also stressed the needs of the children and that more support was required³³⁸.

In a UK study focusing on the use of home treatment teams for older people, they found that using crisis resolution and home treatment teams (CRHTT) significantly reduced admissions, but there was no significant difference in the length of hospital stay as compared before and after the introduction of the service³³⁹. They also found a trend towards carers, but not patients, being more satisfied with treatment after the introduction of the CRHTT. Despite the study's positive findings, it was heavily criticised by other academics. In one of the criticisms published by the journal, Pelosi (2009)³⁴⁰ claimed they had interpreted the results incorrectly, and that there was, in fact, a slight increase in admissions and a substantial increase in proposed admissions after this service was made available. Therefore, the findings from this study should be viewed with caution. A more recent systematic review assessed the effectiveness of crisis resolution/home treatment teams for older people with mental health problems³⁴¹. The review could not determine the effectiveness due to lack of evidence.

Helplines

Only one helpline study was identified. The study, conducted in India, used a helpline available 24 hours a day to identify those most at risk³⁴². The helpline was used to identify patients with suicidal ideation and offer them 12 months of counselling. The study authors concluded that some first-episode patients of schizophrenia and other disorders do access services by using helplines. However, the study sample was small and the transferability to the UK is very limited. In the UK, helplines are already provided by third sector organisations, such as the Samaritans.

Consumer providers

A recent study examined whether employing mental health consumers as consumer-providers in assertive community treatment teams can enhance outcomes for clients with severe mental illness³⁴³. In the longitudinal study, presence of consumer-providers and outcomes of 530 clients with severe mental illness in 20 outpatient teams were assessed at baseline and at one-year and two-year follow-ups. The study concluded that a positive association was found between consumer-provider presence and improvements in functioning. However a negative association was found for the number of hospital days.

³³⁸ Ostman M; Hansson L Children in families with a severely mentally ill member. Prevalence and needs for support. *Social Psychiatry & Psychiatric Epidemiology*, May 2002, vol./is. 37/5(243-8).

³³⁹ Dibben, Claire; Saeed, Humera; Stagias, Konstantinos; Khandaker, Golam Mohammed; Rubinsztein, Judy Sasha. Crisis resolution and home treatment teams for older people with mental illness. *Psychiatric Bulletin*, July 2008, vol./is. 32/7(268-270).

³⁴⁰ Pelosi, Anthony J. Crisis resolution and home treatment teams for older people. *Psychiatric Bulletin*, February 2009, vol./is. 33/2(75-76).

³⁴¹ Toot S; Devine M; Orrell M The effectiveness of crisis resolution/home treatment teams for older people with mental health problems: a systematic review and scoping exercise. *International Journal of Geriatric Psychiatry*, 01 December 2011, vol./is. 26/12(1221-1230).

³⁴² Shrivastava, Amresh K; Johnston, Megan E; Stitt, Larry; Thakar, Meghana; Sakel, Gopa; Iyer, Sunita; Shah, Nilesh; Bureau, Yves. Reducing treatment delay for early intervention: Evaluation of a community based crisis helpline. *Annals of General Psychiatry*, July 2012, vol./is. 11/, 1744-859X

³⁴³ van Vugt MD; Kroon H; Delespaul PA; Mulder CL Consumer-providers in assertive community treatment programs: associations with client outcomes. *Psychiatric Services*, 2012, vol./is. 63/5(477-81), 1075-2730.

Community Mental Health Centres

A US study evaluated Community Mental Health Centres (CMHCs) providing outpatient services in a small area of Iowa. The study found little evidence that differences in staffing and service variables influenced admission rates, although greater CMHC staff coverage by social workers and psychiatric residents was associated with lower admission rates. The results suggest that CMHCs do not lower an area's hospitalization rate, and in fact, the presence of CMHCs may promote a "supplier-induced demand" phenomenon of higher admissions³⁴⁴.

Treatment directives/joint crisis plans

A review is currently being conducted for the COCHRANE Library to review the impact of joint crisis plans, however it is yet to be completed. Therefore, only two papers were identified which tested the impact of joint crisis plans/treatment directives.

An advance treatment directive is a document that specifies a person's future preferences for treatment, should he or she lose the mental ability to make treatment decisions (lose capacity). They have traditionally been used to stipulate treatment in end-of-life situations. However, people with mental health problems can also have periods where they are unable to make treatment decisions, and an advance statement could help with choosing suitable medication, saying who should look after children and specifying choices in other areas of their life and treatment.

One review looked at whether having an advance statement lead to less hospitalisation (either voluntary or involuntary), less contact with mental health services and whether there is an improvement in general functioning³⁴⁵. Two studies were identified, involving a total of 321 people. Both took place in England. One trial involved the person concerned making a joint crisis plan in collaboration with the psychiatrist, care coordinator and project worker (high intensity), while the other required filling in a booklet called 'preferences for care' (low intensity). Both studies were compared to the usual care in the area concerned.

Those who filled in the booklet showed no decrease in admission to hospital (voluntary or involuntary) or contact with out-patient services, when compared to usual care. The high intensity group showed no differences in voluntary admissions compared to those in usual care, but were less likely to be hospitalised involuntarily, or assessed under the Mental Health Act. They were also less likely to be violent. There was no difference in use of psychiatric out-patient services by those in the intervention groups. These are small studies and more research is needed, but it is suggested that using an advance treatment directive could be an alternative to community treatment orders.

The second study was a randomised controlled trial which assessed whether a joint crisis plan reduced the use of inpatient services, and compulsory admission³⁴⁶. The trial found that at 15 months, people with a joint crisis plan were significantly less likely to experience

³⁴⁴ Hendryx MS; Rohland BM A small area analysis of psychiatric hospitalizations to general hospitals. Effects of community mental health centers. *General Hospital Psychiatry*, September 1994, vol./is. 16/5(313-8).

³⁴⁵ Campbell Leslie Anne, Kisely Steve R. Advance treatment directives for people with severe mental illness. *Cochrane Database of Systematic Reviews*. 2009, 1.

³⁴⁶ Kisely S. A joint crisis plan negotiated with mental health staff significantly reduces compulsory admission and treatment in people with severe mental illness. *Evidence Based Mental Health*, 01 February 2005, vol./is. 8/1(17-17).

compulsory admission and treatment (13% v 27%, RR 0.48, 95% CI 0.24 to 0.95) and there was a trend towards fewer overall admissions compared with control (30% v 44%, RR 0.69, 95% CI 0.45 to 1.04). The mean length of hospital stay after compulsory admission was also significantly less for people with a joint crisis plan than controls.

Implications for policy makers and commissioners

In addition to the evidence detailed above, highlighting the impact of certain interventions, implications for policy makers and commissioners can be drawn from a number of other studies. These are presented below under the following heading:

2. Assessing need
3. Staff training

Assessing need

Two scales have been developed in order to assess whether a patient needs to be allocated a bed on a psychiatric ward. One of the scales was tested with two hospitals in West London³⁴⁷. The Bed Requirement Inventory (BRI) is an eight-point scale which can be completed by a member of the ward staff, usually a nurse, and takes 5 minutes to fill in. Based on the findings of a year-long study, the researchers concluded that BRI was a reliable method of determining the appropriate use of a psychiatric bed, and was quick to administer.

The other scale is the Crisis Triage Rating Scale. Brooker *et al.* (2007) used the scale over a six month period³⁴⁸. The study concluded that Crisis Triage Rating Scale may be a useful brief alternative to Health of the Nation Outcome Scale. The study also highlighted the valuable role of mental health nurses in frontline emergency mental health care in particular mental health nurses skills in conducting a risk assessment in an emergency.

Staff training

Hanafi *et al.* conducted a small qualitative study to evaluate the effectiveness of Crisis Intervention Team (CIT) training for police officers³⁴⁹. The study found that officers had increased knowledge of mental illnesses and greater empathy toward consumers and their caregivers, and fewer arrests. The authors believed that these results highlight the potential for collaboration between law enforcement (and other public safety/criminal justice professions) and the mental health professions in the expanding CIT collaborative model.

Informing policy

To address the problem of psychiatric boarding in the US (defined as psychiatric patients' waiting in hallways or other emergency room areas for inpatient beds), a seven-point plan was developed to inform policy decisions around this in America³⁵⁰. The points are outlined

³⁴⁷ Tyrer P; Suryanarayan G; Rao B; Cicchetti D; Fulop N; Green J; Roberts F; Slaughter J. The bed requirement inventory: a simple measure to estimate the need for a psychiatric bed. *International Journal of Social Psychiatry*, May 2006, vol./is. 52/3(267-77).

³⁴⁸ Brooker C; Ricketts T; Bennett S; Lemme F Admission decisions following contact with an emergency mental health assessment and intervention service. *Journal of Clinical Nursing*, July 2007, vol./is. 16/7(1313-22).

³⁴⁹ Hanafi S; Bahora M; Demir BN; Compton MT. Incorporating Crisis Intervention Team (CIT) knowledge and skills into the daily work of police officers: a focus group study. *Community Mental Health Journal*, 01 December 2008, vol./is. 44/6(427-432).

³⁵⁰ Alakeson V; Pande N; Ludwig M. A plan to reduce emergency room 'boarding' of psychiatric patients. *Health Affairs*, 01 September 2010, vol./is. 29/9(1637-1642).

in Box 1 (overleaf). As it is developed for the US, some of the points are not applicable to the NHS system, for example, step #7 has less relevance. However, some clear recommendations are made, including:

4. Train security staff in de-escalation techniques
5. Set up appointment and medication reminders
6. Community mental health clinicians train ED staff in psychiatric patient care
7. Train police officers to recognise and de-escalate mental health crises

Conclusions/Recommendations

- The needs of children should be considered in the planning of home treatment for psychiatric crises.
- There is insufficient evidence to support the use of help lines and 'consumer providers'.
- A tested scale should be used to determine a patient's bed needs.
- The use of home treatment teams can lead to a reduction in in-patient admission rates.
- De-escalation techniques are useful skills for a variety of hospital staff to have, including security teams. Police officers can also benefit from having these skill sets.
- Joint crisis plans can improve outcomes and satisfaction for patients and their families.

Step 1: Quantify and Monitor. Have statistics including how long patients are waiting, and how many could have been seen in an outpatient setting.

Step 2: Improve Emergency Departments Care for Psychiatric Patients. Small, low-cost changes can make a big difference. For example, hospitals that participated in an Institute for Behavioural Healthcare Improvement learning collaborative found ways to reduce length of stay and do low-cost interventions like train clinical and security staff in de-escalation techniques.

Step 3: Make More Efficient Use of Existing Capacity. Utilisation-review teams have helped hospitals improve patient discharge times. At the community level, better management of mental health patients – such as appointment and medication reminders – helps promote timely access to care, and thus reduce the need for emergency department (ED) care.

Step 4: Implement Low-Cost Collaboration Between EDs and Community Outpatient Alternatives. Community mental health clinicians train ED staff in psychiatric patient care, and have a social worker in the ED to connect patients with community services upon discharge. Other recommendations include: additional training about how to improve care for psychiatric patients, collaborate with the police department, hire a social worker to facilitate the use of community alternatives, and work with outpatient facilities to identify frequent ED users.

Step 5: Work With Law Enforcement. Law enforcement officers are often the first responders in cases involving people with mental illness, so they can play an important role in keeping inappropriate cases out of the ED. For instance, the crisis intervention team approach trains officers to recognise and de-escalate mental health crises.

Step 6: Invest in Comprehensive Community Crisis Services. The lack of mental health infrastructure forces these patients to seek care in the ED. To address this issue, develop a Comprehensive Emergency Psychiatric Program which includes a 24-hour help line, mobile crisis outreach team, and a stabilisation unit with beds.

Step 7: Invest in Continuity of Care. While community-based crisis services could replace some ED services, ongoing care at the community level can circumvent many mental health crises that would otherwise end up in the ED and help stem the “revolving door” syndrome where a patient returns repeatedly to the ED. The Medicaid Health Home Option of the Patient Protection and Affordable Care Act of 2010 can help achieve this continuity of care by providing funding for coordinated care through a health home.

RECOVERY: A REVIEW OF THE LITERATURE

Scope

This paper reports the findings of a review conducted to answer four questions in relation to recovery:

1. What does the evidence say are the approaches to recovery that are most effective in promoting choice and control for service users? What are the approaches to recovery that most effectively promote the sense amongst service users that they are able to access a holistic mental health service, and not one which is focused solely on medical management?
2. What does the evidence say are the specific actions that providers (both clinical and non-clinical) can take to deliver these approaches in practice?
3. What does the evidence say are the specific actions that commissioners can take to most effectively incentivise providers to deliver these approaches in practice?
4. What does the evidence say are the effective interventions to support people with mental health problems, considering those with a common mental health problem and those with a serious mental illness, to maintain or return to employment? What are the effective interventions to promote a healthy workplace?

This review looks to answer each of the questions focusing on those identified as common mental disorders³⁵¹, for example obsessive-compulsive disorder, and/or highest rates of mortality, for example, severe depression (uni-and bipolar).

It was not possible to conduct a systematic review due to the time constraints, therefore the quality of the studies was not assessed and no meta-analysis was conducted. However, a systematic search was performed using the well-established databases, such as EMBASE and MEDLINE. This proved a challenge due to the ambiguity of some of the wording used in the questions and therefore a difficulty in establishing the relevant MeSH terms. Despite the review's limitations, a number of relevant studies were identified, and useful conclusions made.

Introduction

Recovery from mental illnesses has been defined as:

"... a deeply personal, unique process of changing one's attitudes, values, feelings goals, skills, and/or roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness."
(Anthony, 1993).

Recovery is about building a meaningful and fulfilling life, as defined by the person themselves, regardless of whether there are ongoing or recurring symptoms or problems. It is about (re)discovering a sense of personal identity, separate from illness or disability. Recovery is often described as a journey, with its ups and downs, and people often describe themselves as being in recovery rather than recovered.³⁵²

While there are many values that may be associated with recovery-oriented services, there are at least four key values that support the recovery process and that appear to be

³⁵¹ Based on findings from the Adult Psychiatric Morbidity Survey, 2007. Accessed at: <http://www.ic.nhs.uk/webfiles/publications/mental%20health/other%20mental%20health%20publications/Adult%20psychiatric%20morbidity%2007/APMS%2007%20%28FINAL%29%20Standard.pdf> Accessed October 2012

³⁵² South London & Maudsley NHS Foundation Trust and South West London & St George's Mental Health NHS Trust (2010) *Recovery is for all: Hope, agency and opportunity in Psychiatry. A position statement by consultant psychiatrists.* London: SLAM/SWLSTF

commonly reflected in the consumer and recovery literature. These values are: person orientation, person involvement, self-determination/choice and growth potential/hope.^{353,354}

Person orientation

People with mental health illnesses want mental health professionals to express interest in them as a person, rather than just as a patient. Recovery-oriented services focus on achieving people's chosen goals and on their preferences. They encourage people's talents and strengths to be assessed and developed, rather than a narrow focus on their deficits and weaknesses. 'Person orientation' also guides services to promote access to resources and opportunities that exist within the community and outside the mental health system. It links recovery with social inclusion and participation in wider society, rather than in segregated communities.

Person involvement

Consumer involvement in planning and delivering mental health services is seen as critical to developing a sense of empowerment and shifting self-identity. Partnership and collaboration between service providers and service users is encouraged and facilitated in the recovery process.

Self-determination/choice

Self-determination and choice are the foundations of a recovery process. Related with self-management, it refers to people gaining a sense of control over their own problems, the services and medication they receive and their own lives. Recovery-oriented services provide the opportunity to choose one's long-term goals, the methods used to achieve those goals and the individuals or providers who will help in the process.

Growth potential/hope

Hope for the future is central to recovery, as recovery is probably impossible without hope. It is therefore essential to help build and sustain motivation, support aspirations (e.g. to complete further education) and facilitate goals (e.g. to get married or to have a family).

Recovery ideas are now a core part of Department of Health policy and are supported by other mental health professional bodies in the UK and abroad. The challenge to mental health professionals is to translate the concepts of recovery into practice, in ways that help service users achieve the goals and outcomes that matter to them (i.e. of personal recovery).

Methods

Studies meeting the following criteria were included in the review:

- d. *Publication type*: Due to time limitations, where possible, only reviews were used. However, if the reviews identified were dated or had a poor search strategy, the following publication types were included: randomised controlled trials (RCTs), non randomised control trials, non-systematic reviews, comparative studies, qualitative studies, case reports and presentations from experts³⁵⁵.
- e. *Participants*: Male and female adults aged 18 years+.

³⁵³ Farkas M (2007). *The vision of recovery today: what it is and what it means for services*. World Psychiatry 6: 68-74

³⁵⁴ South London & Maudsley NHS Foundation Trust and South West London & St George's Mental Health NHS Trust (2010) *Recovery is for all: Hope, agency and opportunity in Psychiatry. A position statement by consultant psychiatrists*. London: SLAM/SWLSTF

³⁵⁵ The order of study prioritisation was based on Hierarchy of evidence used by the Cochrane collaboration.

- f. *Language and country or origin:* Where there was a strong body of evidence from the UK, this was focused upon. Only where there was limited UK evidence, did the search include studies focused on interventions in other countries, such as the USA. Only studies written in English were included.

Search strategy:

A systematic search was conducted using of six electronic databases to identify relevant studies on recovery from mental illness – PubMed, Web of Science, CINAHL, EMBASE, PsycINFO and the Cochrane Library. We searched for papers published in English between 1992 and 2012 using the keywords and combinations of keywords set out under each of the key questions below. The reference lists of all included studies were reviewed to identify additional articles. In addition, a search engine was used to identify any relevant reports and research studies conducted by relevant third sector organisations and government departments.

The MEDLINE search was conducted on PubMed using MeSH search terms, such as mental disorders[MeSH].exp OR mental OR psychiatr*. The search terms were adapted for the other databases.

Findings

1. **What does the evidence say are the approaches to recovery that are most effective in promoting choice and control for service users? What are the approaches to recovery that most effectively promote the sense amongst service users that they are able to access a holistic mental health service, and not one which is focused solely on medical management?**

Based on available literature, we examined a number of specific interventions that most people agree would support a recovery approach in terms of their effectiveness in producing recovery-relevant outcomes. The focus of this review was not on effectiveness in producing clinical outcomes (e.g. relapse, hospitalisation, adherence with medication), but on the dimensions of recovery (particularly choice, control and empowerment) outlined in the introduction.

Shared decision making

Shared decision making (SDM) is a process of collaboration in which clinicians and patients work together to select appropriate treatment, management or support options, based on clinical evidence and the patient's informed preferences. It involves providing evidence-based information about options, outcomes and uncertainties, along with decision support counselling and a system for recording and implementing patients' informed preferences. The clinician's role is not to ensure compliance, but to help the client learn to use medications and other coping strategies, ideally in the process of learning to manage his/her own illness. With its focus on mutual information sharing and respect for individual preferences, SDM can be an empowering experience.³⁵⁶

Studies on SDM in mental health have focused primarily on schizophrenia and depression, and have examined consumers' preferences, experiences with decision-making and effects of specific SDM interventions. Overall these studies show that mental health consumers are generally interested in information and involvement in decision-making, and often want more

³⁵⁶ Deegan PE, Drake RE (2006). *Shared Decision Making and Medication Management in the Recovery Process*. *Psychiatric Services* 57: 1636-1639.

participation compared to what they experienced.³⁵⁷

Results of intervention studies that have incorporated SDM on different levels support the positive impact of SDM, including improved treatment adherence, satisfaction, knowledge, involvement in and activation of decision-making, social functioning, and reduced psychological distress and hospitalisation. A RCT comparing a SDM programme (decision aid, training of physicians and nurses) with routine care of schizophrenic in-patients showed increased knowledge and higher perceived involvement, without increasing physician time workload. In another RCT comparing physician training and a decision aid to usual care in primary care of depression, physicians' facilitation of patient participation improved significantly and patient satisfaction at post-intervention was higher in the intervention group. Results of short-term pilot-testing of a patient-centred decision support intervention for depression in people with diabetes showed increases in knowledge, decision stage and activation of decision-making.³⁵⁸

Of course, there are situations in which shared decision making may not be achievable, such as in emergency situations or in situations in which there is temporary decisional incapacity. In such situations, joint crisis plans or psychiatric advance directives can help protect client autonomy and provide practitioners with a guide to making treatment decisions that are guided by clients' preferences and values.

Joint crisis plans

A joint crisis plan (JCP) is a record containing a service user's treatment preferences for the management of future psychiatric crises, when s/he may be less able to express clear views. A JCP is created by the service user with the help of his/her treating mental health team (thereby increasing the likelihood that it will be implemented), while a psychiatric advance directive may be created without provider input. The JCP is disseminated, with the service user's permission, both to informal caregivers and services the user may attend for emergency care, to maximise its chances of use.

The methods used to develop the JCP are consistent with user-centred care and shared decision making. It aims to empower service users by ensuring that they are actively involved in their own treatment. Information is shared about previous episodes of illness and treatment, as experienced by the service user and observed or recorded by providers. Information is also shared about future care, in the form of service users' preferences and providers' recommendations. An independent mental health professional negotiates the content between the service user and professionals involved. The role of this facilitator is crucial in ensuring that information supplied by providers is not limited or biased, and in ensuring mutual acceptance of the JCP content by service user and providers.

JCPs have been shown to be an effective way of reducing compulsory treatment in people with psychosis, help service users feel more in control of their mental health problems and may also reduce admission rates to hospital. A single blind RCT of patients receiving psychiatric treatment in southern England³⁵⁹ found that use of a JCP significantly reduces use of the Mental Health Act. A health economic analysis of this trial³⁶⁰ has shown that the intervention is highly likely to be cost-effective. In addition, findings from interviews with participants in the intervention group suggest that participants felt more in control of their mental health care as a result of developing the JCP.³⁶¹

³⁵⁷ Simon D, Willis CE, Harter M (2009). *Shared decision-making in mental health*. In A. Edwards & G. Elwyn (Eds.) *Shared decision-making in health care: Achieving evidence-based patient choice* (2nd edition pp.269-276). Oxford: Oxford University Press.

³⁵⁸ *ibid*

³⁵⁹ Henderson C et al (2004). *Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial*. *BMJ* 329:136.

³⁶⁰ Flood C et al (2006). *Joint Crisis Plans for People with Psychosis: Economic Evaluation of an RCT*. *BMJ* 333:729-732.

³⁶¹ Henderson C et al (2009). *Views of service users and providers on joint crisis plans: single blind randomized controlled trial*. *Soc Psychiatry & Psychiatr Epidemiol* 44:369-376.

Personal and individual budgets

The use of personal budgets (PBs) is a key way of achieving personalisation and control within health and social care services. Individuals are supported to assess their own needs, so that a care coordinator can determine if they are eligible for social care funding. If eligible, individuals can use their allocated funding to design and purchase their own care and support from the public, private or voluntary sectors. Service users can either take their PB as a direct payment or ask their care coordinator or someone else to manage the money for them. They can also transfer money to an organisation that currently provides services they want to use.³⁶²

Individual budgets (IBs) are similar to PBs, but incorporate a number of different funding streams in addition to social care funding. The funding streams that could be incorporated include: Access to Work, Supporting People, Independent Living Fund, Integrated Community Equipment Services, and Disabled Facilities Grants.

A national pilot of IBs established by the Department of Health took place in 13 English local authorities from 2005 to 2007 across different groups of social care users; 14 per cent of pilot sample were mental health service users. Overall, the pilot study concluded that people receiving IBs felt more in control of their daily lives, compared to those receiving conventional social care support and were more likely to commission their support from within mainstream community facilities, rather than specialist services. Those with mental health support needs had the most positive outcomes in overall wellbeing and a tendency towards better psychological health. IBs also offered this group a greater range and flexibility of support arrangements than conventional services, as well as a more holistic, person-centred service.³⁶³

Peer support

Peer support involves the use of others with lived experience of mental health problems acting as workers who directly help others with similar problems. Peer support is based on the belief that people who have faced, endured and overcome adversity can offer useful support, encouragement, hope and mentorship to others facing similar situations.

There are now a number of studies of peer support interventions which show that appropriately trained and supported peers can increase service users' satisfaction; their sense of control, empowerment and movement towards recovery. They can also help the person expand their social networks, gain hope and become more involved in their own care.³⁶⁴

A recent comprehensive review³⁶⁵ of peer support among adults with mental health difficulties found a broad range of effects of receiving peer support. These include not just clinical effects, such as quality of life or the hospitalisation rate, but also personal and emotional effects, such as feelings of understanding or trust. Many users felt respect, humanity and trust and related to consumer-providers more readily than traditional staff, which facilitated user engagement and satisfaction. Consumer-providers also empowered patients to be more outspoken about pursuing their own goals.

In addition to the benefits of peer support for recipients, some research has focused on the benefits to peer-support providers. Providers' benefits include self-efficacy resulting from helping others, personal growth (specifically increased self-knowledge) due to

³⁶² Mind (2009). *Personalisation in mental health: A review of the evidence*.

³⁶³ Glendinning C et al. (2008). *Evaluation of the Individual Budgets Pilot Programme: Final Report*. York: Social Policy Research Unit, University of York.

³⁶⁴ Miyamoto Y, Sono T (2012). *Lessons from Peer Support Among Individuals with Mental Health Difficulties: A Review of the Literature*. *Clin Pract Epidemiol Ment Health* 8: 22–29.

³⁶⁵ Repper J, Carter T (2011). *A review of the literature on peer support in mental health services*. *Journal of Mental Health* 20(4): 392–411.

communicating with others sharing similar experiences, development of skills, improved communication abilities, increased confidence and gaining a sense of identity. An opportunity to contribute to the recovery of others contributes to providers' own recovery. Many peer support providers mentioned the benefit of earning money. Although payment status did not affect peer support satisfaction, it was associated with more positive recovery attitudes, spirituality and engagement in meaningful activities.

2. What does the evidence say are the specific actions that providers (both clinical and non-clinical) can take to deliver these approaches in practice?

The aim of this section is to identify some tangible actions providers can take to provide mental health service users with a more holistic experience, namely through transforming services into recovery-oriented ones. The intention was not to provide step-by-step instructions for providers, which is beyond the scope of this review, but to provide some suggestions for good practice.

We did a search for what actions providers can take to deliver the different recovery-oriented approaches identified in question one. As most of these approaches are broad and attract a large number of papers, conducting a full, systematic review of the evidence for each approach was not possible within the scope of this review. We therefore sought out recent papers that reviewed and drew on a broad base of evidence to describe practical implications and recommendations for service provision. Given that many of the approaches identified in question one are relatively new in the mental health field and lack controlled, comparative tests to identify which process-related factors contribute to effective implementation, 'evidence' often included narrative accounts (views or lessons learned) from experts, practitioners and/or users involved in practical implementation.

Shared decision making

A recent report by Coulter and Collins³⁶⁶ for The King's Fund aims to help embed SDM and make effective SDM the norm. Drawing on a number of studies investigating clinicians' attitudes towards SDM, the report identifies a number of commonly voiced objections to the approach and offers some solutions. These include:

- Information (preferably personalised) should be provided to patients, along with decision support, personalised care planning and self-management education from well-trained health professionals, as well as social support from family, friends and peers;
- Evidence-based decision aids should be used during encounters to initiate SDM with patients, or provided to patients, their family and friends to use outside meetings in their own time. Decision aids range from simple summary sheets outlining the choices, to more detailed booklets, computer programs, DVDs or interactive websites. Service providers (and users) can access a large number of practical tools, best practice strategies and evidence to help implement SDM on the Health Foundation's online SDM resource centre (<http://shareddecisionmaking.health.org.uk>); and
- Service providers should adopt a consulting style that is enquiring, supportive and non-judgemental, using helpful tips like those listed below from the Sainsbury Centre for Mental Health's 10 top tips for Recovery-oriented practice (Box 1).³⁶⁷

³⁶⁶ Coulter A, Collins A (2011). *Making shared decision-making a reality: No decision about me, without me*. London: Kings Fund.

³⁶⁷ Shepherd G, Boardman J, Slade M (2008). *Making Recovery a Reality*. London: Sainsbury Centre for Mental Health.

Understand recovery

1. Help the person identify and prioritise their personal goals for recovery (not the professional's goals)
2. Demonstrate a belief in the person's existing strengths in relation to the pursuit of these goals
3. Be able to identify examples from your own lived experience, or that of other service users, which inspires and validate hope.
4. Accept that the future is uncertain and that setbacks will occur, continue to express support for the possibility of achieving these self-defined goals – maintaining hope and positive expectations.

Know how to collaborate

5. Encourage self-management of mental health problems (by providing information, reinforcing existing coping strategies, etc.)
6. Listen to what the person wants in terms of therapeutic interventions, e.g. psychological treatments, alternative therapies, joint crisis planning, etc. Show that you have listened.
7. Behave at all times so as to convey an attitude of respect for the person and a desire for an equal partnership in working together.
8. Indicate a willingness to 'go the extra mile' to help the person achieve their goals.

Have a broad view

9. Pay particular attention to the importance of goals which take the person out of the traditional sick role and enable them to serve and help others.
10. Identify non-mental health resources – friends, contacts, organisations – relevant to achievement of these goals.

Joint crisis plans

Providers can help minimise the loss of service users' personal responsibility during crisis by routinely developing JCPs ahead of crisis, and making sure the service user's treatment preferences are actually implemented during crisis. JCPs should include identification of early signs of an impending crisis, how to draw on the individual's own resources and those of others, and how and where to get help if the situation deteriorates.

Interviews with those who produced a JCP in the 2004 single blind RCT³⁶⁸ found that while the experience of creating a JCP was for most participants a very positive one, by 15 months follow up their experiences were more mixed. For some that did experience a crisis, their preference statements were not always followed – either because clinicians felt they were not in the holder's best interest or they did not know about them, or because the JCP content was vague enough to allow different interpretations of when and how to act on the service users behalf.

To help ensure effective and sustained use of the JCP, the content should be periodically reviewed with holders, including after a crisis, so that learning from the crisis about the illness and experience of care can be applied. The extent of shared decision making should

³⁶⁸ Henderson C et al (2009). Views of service users and providers on joint crisis plans: single blind randomized controlled trial. *Soc Psychiatry & Psychiatr Epidemiol* 44:369-376.

be broadened (e.g. by using patient decision aids) to ensure treatment plans for routine care are also aligned with service user's goals, preferences and values.

Personal and individual budgets

Service providers should encourage and support people to access and manage personal budgets. A 2009 review³⁶⁹ of academic, practitioner and policy literature about the use of PBs and direct payments by people who use mental health services identified a number of concerns and challenges, with suggestions for ways forward. These include:

- Frontline staff should have access to better targeted training and support (e.g. in assessment, support planning and brokerage; ways of deploying and managing budgets; legal responsibilities; financial and risk management), so that they feel confident working with PBs and encourage greater take up of PBs;
- Recruitment, training and conditions of employment for personal assistants (PAs) are important, particularly because the relationships they develop with PB recipients are often necessary to deliver the control and flexibility that recipients require;
- Develop effective support schemes for people using PBs, which could include specialist advocacy support and user-led initiatives that provide support;
- Increase awareness and better use of specific tools developed in the mental health field, including crisis planning, self-assessment diaries and guidelines for PAs to follow if the PB recipient becomes unwell;
- Improve joint working at local level, including better links between health and social care, and more transparency and better communication through cross-sector working groups; and
- Develop monitoring and review systems to reduce risks of abuse and neglect and allay concerns about risks for PB users, both when approving support plans initially and on an ongoing basis.

Recent research on the experiences of 69 PB holders and carers, supported by the views of 40 practitioners and managers and 12 support provider organisations provides more evidence to inform good practice in PB processes for people with mental health problems (and older people).³⁷⁰ These include:

- More consistent, tailored support in the assessment and support planning processes, with assessments focused on outcomes and addressing individual strengths and aspirations as well as needs;
- Active involvement of practitioners in encouraging people to think beyond traditional service models and develop creative ideas about how to meet their needs;
- Ensuring staff have time to discuss different options with potential PB holders – fully to begin with (including advice on the risks of alternative treatments so unsuitable options can be ruled out early on) and more than once;
- Providing opportunities for PB holders to share their experiences with potential PB holders, and with other PB holders about how they were using their PBs; and
- Training and development work with existing providers to help them understand the principles and practice of PBs and encourage them to adapt their services.

Lessons have also been drawn from in Control's pioneering work, including a pilot of PBs and self-directed support with a wide range of social care users across six local authorities from 2003 to 2005.³⁷¹ Recommendations for providers include:

³⁶⁹ Norah Fry Research Centre at the University of Bristol (2009). *Personalisation in mental health: A review of the evidence*. London: Mind.

³⁷⁰ Newbronner L et al (2011). *Keeping personal budgets personal: Learning from the experiences of older people, people with mental health problems and their carers*. Accessed at: www.scie.org.uk/publications/reports/report40/index.asp on 9 Nov 2012.

³⁷¹ Hatton C et al (2008). *A report on in Control's Second Phase: Evaluation and learning 2005-2007*. London: in Control.

- Changing how they use money they receive from commissioners, so that it is dedicated to individuals, not to units or teams
- Changing the criteria for judging quality and success so they are defined by service users, not regulators or managers
- Meeting regularly with commissioners and include service users in some of these meetings (but avoid tokenism) to ensure resource allocation and service design are person-centred

Peer support

Peer support should be available in clinical and community-based teams, either through facilitating the development of mutual self-help groups or peer-run programmes, or employing peer support specialists. Service providers are critical in referring users to peer support programmes.

Two recent systematic literature reviews of peer support in mental health^{372,373} drew on a number of papers to identify effective strategies for implementing peer services. These include:

- Human Resource teams should implement recruitment policies that allow experience in lieu of formal credentials
- Whilst a clear, standardised role description is essential, this needs to be flexible enough to allow peer support workers to use their own experiences of recovery
- Peer positions should be permanent, independent of fluctuations in funding and viewed as essential rather than an add-on
- Peer posts should be compensated and evaluated on the same performance standards as other staff, with opportunities to be promoted
- Peer support positions should come with a wage high enough to compensate for any loss of benefits, and advice should be available to peer support workers about their welfare rights
- Previous treatment records of internally recruited peers should be kept in confidential files
- Clear, consistent policies or a specific code of ethics/conduct need to be developed and implemented to avoid anxieties and complications arising through peer support workers' dual role as 'patient' and 'worker'
- In addition to training specific to their roles in peer support, peer support workers should have access to the range of skills-based training and mandatory health and safety training provided to all staff in many healthcare organisations
- Peer support workers should receive consistent mentoring and supervision, including managerial supervision, mentoring from a senior peer/consumer worker and group supervision to share insights, coping strategies and experiences
- At least two peer support workers should be employed in a team/service to reduce the risk of isolation and coercion to other mental health agendas

3. What does the evidence say are the specific actions that commissioners can take to most effectively incentivise providers to deliver these approaches in practice?

This section aims to identify practical actions commissioners can take to encourage providers to deliver the recovery-oriented approaches identified in question one. We did a similar rapid search as that carried out for question two, but with a focus on lessons for commissioning. As with the previous question, a full, systematic review was not feasible within the scope of this work, so recommendations were sought from papers that had carried

³⁷² Repper J, Carter T (2010). *Using Personal Experience To Support Others With Similar Difficulties: A Review Of The Literature On Peer Support In Mental Health Services*. London: Together.

³⁷³ Davidson L et al (2012). *Peer support among persons with severe mental illnesses: A review of evidence and experience*. *World Psychiatry* 11(2): 123–128.

out more comprehensive reviews in each area.

Shared decision making

Coulter and Collins' recent report³⁷⁴ for The King's Fund on embedding SDM suggests some actions for commissioners. These include:

- Provide incentives for organisations and clinicians to engage patients in SDM, such as a financial incentive for clinicians to make decision aids available to their patients, or require the use of decision aids to achieve performance targets
- Use appropriate performance measures (such as decision quality and patient activation measures) and patient feedback at decision points in care pathways to monitor progress

In addition to the above recommendations, a scoping paper³⁷⁵ produced by Coulter in 2009 for the Health Foundation also suggests establishing virtual preference laboratories where patients could view decision aids on a website, receive decision support by telephone and answer a few key questions to check their knowledge, values and preferences. An automated report could be sent to the clinician informing them of the patient's preferences and concerns, allowing appointment time to be used more efficiently and promote more patient-centred care.

Joint crisis plans

There appears to be a lack of evidence around what specific actions commissioners can take to most effectively incentivise providers to work with service users to develop JCPs.

Personal and individual budgets

Evaluations of the national IB pilot programme³⁷⁶ and in Control's extensive work around PBs and self-directed support³⁷⁷ have offered several lessons for commissioners, such as:

- Work together with senior managers to ensure that money is allocated individually in a fair and transparent way
- Find alternatives to block contracts and impersonal care, with the development of a resource allocation system (RAS) in each locality. On expiry of any block contract, commissioners should take the opportunity to specify more individual arrangements rather than setting up larger, longer-term contracts that may seem to give better value now
- Support people to make good, informed decisions with their budgets, whether state or self-funded, e.g. by ensuring a wide range of support brokerage options are available and investing in online market navigation tools
- Support people to come together and commission their own support through consortium arrangements whereby they pool their resources
- Make information available to the market about IB recipients' preferences and spending patterns so that providers can adapt and respond
- Build constructive partnerships with providers and support them through the transition to different ways of working, e.g. training in person-centred approaches, support with changing finance, HR and marketing functions
- Develop local partnerships, particularly between health and social care, and support innovation in the third and private sector to produce a range of services for people to choose from
- When reviewing services, there should be a focus on how they have helped to

³⁷⁴ Coulter A, Collins A (2011). *Making shared decision-making a reality: No decision about me, without me*. London: Kings Fund.

³⁷⁵ Coulter A (2009). *Implementing shared decision making in the UK*. London: Health Foundation.

³⁷⁶ Glendinning et al (2008). *Evaluation of the individual budgets pilot programme: Final report*. York: Social Policy Research Unit, University of York.

³⁷⁷ Hatton C et al (2008). *A report on in Control's Second Phase: Evaluation and learning 2005-2007*. London: in Control.

achieve personal recovery outcomes

- Find ways to interact with and really listen to people who need support by joining and helping to organise community events
- Develop a unified approach to PBs, including a single assessment framework that can coordinate funding from the NHS and social care, and a shared set of agreed outcomes across the two services. Individuals should expect to have only one budget, one support plan and one review process to meet their health and social care needs

Peer support

Repper and Carter's literature review³⁷⁸ on peer support in mental health identifies barriers to peer support and offers recommendations for commissioners, such as:

- Sustainable funding and multi-level support through providing a comprehensive certified range of training options, a clear job description, competencies (tested), professional status, a career pathway and a specific code of ethics
- Introduce training programmes to staff in local statutory mental health services with a focus on the evidence base behind recovery and peer support, benefits of employing peer support workers, how the peer support worker role will fit in with their roles, and the supervision and support needs of peer support workers
- Offer a standardised training programme for peer support workers (ideally peer-led) in the fundamental skills required for their position (such as recovery planning, life coaching, active listening)

4. What does the evidence say are the effective interventions to support people with mental health problems, considering those with a common mental health problem and those with a serious mental illness, to maintain or return to employment? What are the effective interventions to promote a healthy workplace?

There is also a large body of evidence which looks at interventions to promote a healthy workplace, from healthy eating to work station posture. However, due to time limitations, this review has focused upon employees who have had periods of mental ill health related absenteeism and what interventions have most effectively supported the return to work. Studies which have primarily focused on at risk employees or preventative programmes have been excluded.

There is strong evidence, from RCTs undertaken in several different countries and with numerous populations (including people with different diagnoses, educational levels and work histories), for the effectiveness of Individual Placement and Support (IPS), a specific 'place then train' model of vocational rehabilitation. The EQOLISE project compared IPS versus 'train-and-place' vocational rehabilitation in six European countries.³⁷⁹ It concluded that IPS is more effective than the vocational services for all vocational outcomes. IPS clients were twice as likely to gain employment (55% v. 28%), worked significantly more hours, had higher earnings and better job tenure. They were also significantly less likely to have been rehospitalised. In the UK, South West London and St George's Mental Health NHS Trust has used IPS successfully in supporting the employment of people with serious mental health problems.³⁸⁰

³⁷⁸ Repper J, Carter T (2010). *Using Personal Experience To Support Others With Similar Difficulties: A Review Of The Literature On Peer Support In Mental Health Services*. London: Together.

³⁷⁹ Burns T et al (2008). *Individual placement and support in Europe: The EQOLISE trial*. *International Review of Psychiatry* 20(6): 498-502.

³⁸⁰ Rinaldi M, Perkins R (2007). *Implementing evidence-based supported employment*. *The Psychiatrist* 31: 244-249.

A 2005 systematic review³⁸¹ of workplace interventions for people with common mental health problems found that:

- For those employees considered at risk of mental health problems at work, individual rather than organisational approaches to managing common mental health problems are most likely to be effective in enabling this group to stay in work. The most effective programmes focused on personal support, individual social skills and coping skills training. The most long-lasting effects were from multimodal programmes
- For people already experiencing common mental health problems at work, there was strong evidence that the most effective approach is brief individual therapy (up to eight weeks), especially cognitive behavioural therapy (CBT). This helps most for employees who have a greater level of control over their work
- CBT seems to be effective whether delivered face-to-face or via computer-aided software. The computer-aided software approach seems promising, although its effectiveness has currently only been demonstrated in the short term (one month)
- Line managers, occupational health professionals and GPs need to work together to support employees with mental health problems
- While exercise has been shown to help people to manage stress, as yet there is no firm evidence that stress management techniques help people once they have common mental health problems.

Although CBT was deemed effective by a number of studies, one study concluded that no intervention has effects that last forever. It was hypothesised that programmes might be more effective at sustaining changes if they include booster and follow-up sessions³⁸².

The support for health and workplace interventions aimed at return to work, was disputed by a large RCT on employment interventions, the *Job Retention and Rehabilitation Pilot*.³⁸³ The study found no significant differences between the intervention and control groups. The intervention group received one of three interventions:

1. *a workplace intervention*, aimed at achieving a return-to-work by addressing issues in the workplace;
2. *a health intervention*, aimed at achieving a return-to-work by addressing the health issues of the individual; and
3. *a combined intervention*, this being a mix of the above two interventions (the appropriate mix per individual being left to the judgement of the intervention provider).

In the case of those with mental and behavioural disorders, the study stated that 'it appears that the interventions may have actually reduced the likelihood of a return to work' (p 5).

Despite the poor outcomes found by Purdon *et al.*, a systematic rapid evidence assessment conducted in 2007 concluded that there was some evidence to show that the people who participated in the employment interventions found them acceptable and valuable³⁸⁴. The review found that participants in two studies^{385 386} who returned to work felt they would not

³⁸¹ Seymour L, Grove B (2005). *Workplace interventions for people with common mental health problems*. London: British Occupational Health Research Foundation.

³⁸² Reynolds S, Taylor E and Shapiro DA (1993) Session impact and outcome in stress management training. *Journal of Community and Applied Social Psychology*. 3: 325 – 337.

³⁸³ Purdon S, Stratford N, Taylor R, Natarajan L, Bell S, Wittenburg D (2006) Impacts of the Job Retention and Rehabilitation Pilot. Leeds: Department of Work and Pensions.

³⁸⁴ Lisa Underwood, James Thomas, Teresa Williams, Anne Thieba. Systematic rapid evidence assessment: The effectiveness of interventions for people with common mental health problems on employment outcomes. Report no. 1509R · December 2007
http://eppi.ioe.ac.uk/cms/LinkClick.aspx?fileticket=zPcN_4efeU8%3d&tabid=2315&mid=4279
Accessed November 2012

³⁸⁵ Grove B, Seebom P (2005) Employment Retention Project Walsall Evaluation Report. Chapter Five: References 23. London: The Sainsbury Centre for Mental Health.

have done so without the intervention, and even those who did not return felt positively about the projects.

There were a number of barriers and facilitators which supported those with mental health problems either staying in employment or returning after a period of leave. These included:

- Three studies showed that employees preferred to return to work gradually as they were anxious about the impact of work on their health and felt incapable of working a full-time schedule due to mental and physical symptoms^{387 388 389}. The studies by Cows J and Noordik also concluded that during the process of returning to work, the employees needed extra time to practice coping strategies and had to continuously evaluate whether they exceeded their work capacity. Anderson *et al* also found that this gradual approach was needed³⁹⁰.
- The British Occupational Health Research Foundation's review found associations with shorter time to return to work in employees with mental health problems if support from supervisors was well-developed and proactive. There was a particular association if a supervisor had financial or other responsibilities for return to work³⁹¹. In addition to this, Nieuwenhuijsen *et al.* (2004)³⁹² stated that supervisors should keep in touch with employees on mental ill health sickness absence at least once every two weeks.
- The importance of supportive line managers was also a conclusion from the 2009 review conducted by NICE³⁹³. The review made a number of recommendations in regard to support from line managers:
 - a) managers are able to identify and respond with sensitivity to employees' emotional concerns, and symptoms of mental health problems
 - b) promoting a management style that encourages participation, delegation, constructive feedback, mentoring and coaching
 - c) managers are able to motivate employees and provide them with the training and support they need to develop their performance and job satisfaction
 - d) ensuring that managers understand when it is necessary to refer an employee to occupational health services or other sources of help and support
- The NICE review also stressed the need for different options for flexible working include part-time working, home-working, job sharing and flexitime. It was recognised that such opportunities can enhance employees' sense of control and promote engagement and job satisfaction.
- A recent meta-synthesis of eight qualitative studies identified a number of barriers preventing people from returning to work³⁹⁴. These included (i) exhaustion, reduced

³⁸⁶ Thomas T, Secker J, Grove B (2003) Getting Back before Christmas: Avon and Wiltshire Mental Health Partnership Trust Job Retention Pilot Evaluation. London: IAHSF, King's College London.

³⁸⁷ Cows J, Galloway E. Understanding how traumatic re-enactment impacts the workplace: Assisting clients successful return to work. *Work*. 2009;33:401–11.

³⁸⁸ Noordik E, Nieuwenhuijsen K, Vrekamp I, van der Klink JJ, van Dijk F.J. Exploring the return-to-work process for workers partially returned to work and partially on long-term sick leave due to common mental disorders: a qualitative study. *Disabil Rehabil*. 2010;1–11.

³⁸⁹ Saint-Arnaud L, Saint-Jean M, Demasse J. Towards an enhanced understanding of factors involved in the return to work process of employees absent due to mental health problems. *Can J Commun Ment Health*. 2006;25:303–15.

³⁹⁰ Andersen MF, Nielsen KM, Brinkmann S. Meta-synthesis of qualitative research on return to work among employees with common mental disorders. *Scand J Work Environ Health*. 2012;38(2):93–104.

³⁹¹ British Occupational Health Research Foundation Workplace interventions for people with common mental health problems: Evidence review and recommendations. 2005. Accessed at: http://www.bohrf.org.uk/downloads/cmh_rev.pdf Accessed November 2012.

³⁹² Nieuwenhuijsen K, Verbeek J H A M , de Boer A G E M , Blonk R W B and van Dijk F J H (2004) Supervisory behaviour as a predictor of return to work in employees absent from work due to mental health problems. *Occupational & Environmental Medicine* 61:817 –823.

³⁹³ NICE. Guidance for employers on promoting mental wellbeing through productive and healthy working conditions. Public health guidance, PH22 - Issued: November 2009. <http://guidance.nice.org.uk/PH22> Accessed November 2012

concentration, and forgetfulness can be seen as an obstacle at the biological level; (ii) perfectionism, a high sense of responsibility and low self-efficacy can be seen as obstacles at the psychological level; and (iii) low social support and lack of coordination between the systems can be seen as obstacles at the social level.

Conclusions/Recommendations

- Four key values that support the recovery process are: person orientation, person involvement, self-determination/choice and growth potential/hope.
- Shared decision making, joint crisis planning, personal budgets and peer support were specific interventions that most of the literature identified as supporting a recovery approach.
- There are a number of commonly voiced objections to the SDM approach, however a number of solutions have been provided to overcome these concerns, such as the use of decision aids, and the provision of personalised information.
- Service providers should encourage and support people to access and manage personal budgets. To achieve this, frontline staff should have access to better targeted training and support and specialist advocacy support should be developed.
- Peer support should be available in clinical and community-based teams, either through facilitating the development of mutual self-help groups or peer-run programmes, or employing peer support specialists.
- To reduce the gap between intention and implementation, the return to work intervention should not only focus on the coping strategies of the employee but also on the workplace and facilitate social integration of the returned employee. Supervisors support and taking a gradual approach is also needed.

³⁹⁴ Andersen MF, Nielsen KM, Brinkmann S. Meta-synthesis of qualitative research on return to work among employees with common mental disorders. *Scand J Work Environ Health*. 2012;38(2):93–104.

TRANSITION: A REVIEW OF THE LITERATURE

Scope

This paper reports the findings of a review conducted to answer the question:

1. What are the effective interventions to manage transition effectively for children and young people?

This review sets out learning and recommendations in more detail for:

- a) Key vulnerable groups (care leavers and those in care, young people with complex health needs and young people in the youth justice system); and
- b) Transition services for all young people with mental health requirements.

Key recommendations and considerations are also presented at the end of his paper.

Introduction

Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) have undergone significant improvement over the last decade, both in respect of secondary in-patient and community-based services, as well as the interface with primary care. However, concerns about the quality of transition for young people from CAMHS to adult mental health services, or out of mental health services altogether, have existed for some time. Too often these transitions have been poorly planned and managed, resulting in young people aged between 16 and 19 not receiving appropriate services or 'falling through the net'³⁹⁵.

The challenges faced by young people moving from adolescence into adulthood have been well documented. The extra challenges of negotiating service transitions at the same time have received similar attention. What should, for all young people, be a time of increasing independence and opportunity can, for young people with mental health problems, signal a period of uncertainty and even deterioration in their mental health³⁹⁶. This failure to provide suitable health and social care services to meet continuing needs can have a negative impact on longer-term health and well-being of young people.

Methodology

This review was informed by a range of studies, papers and articles that incorporated their own literature reviews and referencing, service user case studies, organisation/service case studies, practitioner guidance and clinical guidance. The authors were guided to the Athens website by the management team and used predominantly material from that source. Additional Internet searches were conducted. The authors focused on recent materials (no

³⁹⁵ <http://www.nmhd.org.uk/silo/files/planning-mental-health-services-for-young-adults--improving-transition.pdf>.

Accessed June 2013

³⁹⁶ *Stressed out and struggling: Two steps forward, one step back*. Pugh, K. McHugh, A. McKinstrie, F. Young Minds 2006. *Transitions, Young Adults with Complex Needs, Social Exclusion Unit Final Report 2005, HASCAS CAMHS to AMHS Transition: Tools for Transition, Right Here* Mental Health Foundation, Minority Voices, Street et al, YoungMinds 2005

more than ten years old), focused on generic provision, and the needs of particularly vulnerable groups. No further information was available from the authors.

Findings

In 2009, Singh, a professor at the University of Warwick, published a paper which has been influential in informing subsequent guidelines³⁹⁷. The review was a synthesis of current research and policy literature on transition to determine the magnitude of the problem, barriers at the interface between CAMHS and AMHS and outcomes of poor transition. It found that adolescence is a risk period for emergence of serious mental disorders. CAMHS and AMHS use rigid age cut-offs to delineate service boundaries, creating discontinuities in provision of care. Adolescent mental health services are patchy across the world. Several included studies confirmed that problems occur during transition in diverse settings across several countries. In physical health, there are emerging models of practice to improve the process and outcomes of transition, but there was very little comparable literature in mental health care.

The author summarised that poor transition leads to disruption in continuity of care, disengagement from services and is likely to lead to poorer outcomes. Some young people, such as those with neurodevelopmental disorders and complex needs, are at a greater risk of falling through the care gap during transition. Services need robust and high quality evidence on the process and outcomes of transition so that effective intervention strategies can be developed.

Transition in Mental Health for specific vulnerable groups

*a) Young People with complex health needs*³⁹⁸

A study by the University of York Social Policy Research Unit found that the transition support to adult services for children and young people requiring an on-going service varied but for particular groups there was a body of evidence to suggest transition is problematic. This included disabled young people and those with complex health needs. This is despite the fact that transition features in a number of government policies aimed at these groups and despite the fact that there are in place a number of multi-agency transition services, transition remains problematic for many of these young people.

The research study mentioned above (referenced in footnote 4) aimed to explore good practice in the development and delivery of multi-agency co-ordination transition services for disabled young people and those with complex health needs and their families. The study focused on reviewing five different service models and the associated outcomes for young people and parents. The study found that there were a number of factors that resulted in the failure to provide a co-ordinated approach to transition. These included: lack of multi-agency working; lack of a holistic approach; lack of information for young people and parents;

³⁹⁷ Singh (2009). The great divide: Transition of care from child to adult mental health services. http://wrap.warwick.ac.uk/3758/1/WRAP_Singh_current_opinions5.pdf. Accessed June 2013.

³⁹⁸ Sloper *et al.* (2010) Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs: Impact and Cost, The University of York Social Policy Research Unit

insufficient attention to the concerns/priorities of the young person; and lack of appropriate services/provision onto which young people can transfer.³⁹⁹

The study suggests that the most effective transition services have the following characteristics:

- Comprehensive multi-agency engagement
- The full participation of young people and their families
- The provision of high quality information
- Effective transition planning
- An array of opportunities for living life.⁴⁰⁰

The review also offers a number of recommendations that may assist with addressing some of the limitations of multi-agency transition services. These include:

- Multi-agency commitment with senior level involvement in the development and oversight of services;
- A dedicated transition worker and a clear definition of this role which should include cross agency working, role in relation to the young person and their parents and their on-going relationship following transition to adults' services;
- Provision of clear information and engagement with the young person and parents in relation to care planning and opportunities available; and
- Ensure care plans are developed following a holistic assessment of need for all groups of disabled young people (not just those with severe learning disabilities).

The study also concluded that the recent shift in government policy will also go a long way to improving support in the transition into adulthood. *Support and Aspiration: A new approach to special educational needs and disability – progress and next steps* sets out current progress and our further plans for the vision, in which:

- Children's special educational needs (SEN) are picked up early and support is routinely put in place quickly;
- Staff have the knowledge, understanding and skills to provide the right support for children and young people who have SEN or are disabled, wherever they are;
- Parents know what they can reasonably expect their local school, local college, local authority and local services to provide, without them having to fight for it;
- Children who would currently have a statement of SEN and young people over 16 who would have a learning difficulty assessment have an integrated assessment and a single education, health and care plan which is completed in a shorter time and without families having the stress of searching to get the support they need;
- Parents have greater control over the services they and their family use, with:
- Every family with an education, health and care plan having the right to a personal budget for their support; and
- Parents whose children have an education, health and care plan having the right to seek a place at any state-funded school, whether that is a special or mainstream school, a maintained school, academy or Free School.⁴⁰¹

³⁹⁹ Ibid

⁴⁰⁰ Ibid

b) Care leavers

A government commissioned study by the NFER on the provision of mental health services for care leavers: transition to adult services aimed to examine whether this group of young people (particularly those with mental health issues) had achieved better outcomes as a result of developments since the Leaving Care Act 2000. The study found that whilst there is some excellent practice there is still room for improvement in terms of consistency of support for all care leavers. Recommendations arising from the report include:

- Ensuring interim arrangements are in place for care leavers prior to transition to adult services including the extension of children's services until the age of 21;
- Awareness raising and mental health training for those working with care leavers;
- Person-centred, choice based services;
- Locating mental health practitioner in leaving care team; and
- Needs assessment on mental health for all young people leaving care.⁴⁰²

Evidence from the '*Mental Health and Well being in Mind*'⁴⁰³ article states that mental health of looked after children and young people should be focused on, and that for this group of children and young people are more likely to experience mental health problems and poor mental health due to the factors leading to them becoming looked after, such as separation, bereavement, trauma, lack of continuity and stability in care arrangements, combined with the recognised contributing to poor mental health across the child family and wider community.

Two tables from the study provide a summary of the contributing factors for poor mental health and for protective mental health. It is crucial that looked after children and young feel they have control and choice from those caregivers looking after them, and from support services they may be accessing.

Poor mental health in looked after children and young is less readily definable than in those children not looked after. The research recommends that when assessing and diagnosing this group of children, practitioners and support staff ensure that they are aware that a diagnosis may not necessarily emerge from using categorical models of disorder but may instead emerge from concerns elicited by a child's behaviour.

Experienced practitioners suggest that for this population it is more useful to work with concepts of change, trauma, resilience, loss and attachments and to take an ecological view of the presenting behaviour.

c) Young people with eating disorders

The peak age at onset of anorexia nervosa is the mid-teens and that of bulimia nervosa is 2 or 3 years later. The average duration of anorexia nervosa is 6 years. Thus these disorders span the transition between child and adolescent and adult services. A paper by Treasure et

⁴⁰¹<http://www.education.gov.uk/childrenandyoungpeople/send/sen/b0075291/green-paper/progress>, 9

⁴⁰² Local Government Association, provision of mental health services for care leavers: transition to adult services, National Foundation of Clinical Excellence (NFCE), 22

⁴⁰³ With Mental Health and Wellbeing in Mind (Scottish Journal of Residential Childcare 2009)

al. (2005) highlights some of the difficulties faced by service users and their carers⁴⁰⁴. In addition to some of the issues highlighted in other studies regarding the transition between CAMHS and adult services, Treasure *et al.* also discuss the need for dual teams supporting a patient when they leave home to study at university. They claim that the idea of a patient having lengthy but flexible care from two teams while they are students is an anathema to many service providers who prefer to remove patients from 'their books' if they are out of the area for a period. They also stress that treatment for eating disorders cannot be easily compartmentalised to fit within academic terms or holidays. The authors refer to the *Mental Health of Students in Higher Education* report (Royal College of Psychiatrists, 2003)⁴⁰⁵ which they believe provides a useful framework for resolving the difficulties posed. Its list of recommendations includes:

- 'Local mental health teams and counselling and medical services in HEIs [Higher Education Institutions] to work more closely together when jointly supporting those with severe mental health difficulties; to develop frameworks and clear protocols for cross-referral which take account of local mental health and counselling provision and expertise. Student counselling services to participate in the care programme approach (CPA) for students when necessary, although it must be recognised that student counsellors are not mental health workers and cannot fulfil the role of CPA care coordinator;

and

- An enabling policy to allow students to move smoothly between home and university, to ensure continuity of NHS treatment (including CPA) and without arguments about which Trust should pay' ([Royal College of Psychiatrists, 2003](#): p. 55).

Finally the authors recommend that the core competencies of every psychiatrist should include: the ability to assess acute risk (including a medical evaluation) and long-term prognosis, and to know what treatments effectively address these needs.

How effectively does the current system work?

Current therapeutic arrangements for looked after children and young with mental health requirements are not adequately delivered, in part due to the way they are organised, how resources are allocated, waiting times from referral to assessment and the fact that services are delivered in clinical settings which are perceived as stigmatising children and young people⁴⁰⁶. The inadequacy also stems from the different conceptual frameworks on which care services and treatment services are constructed⁴⁰⁷.

⁴⁰⁴ Treasure, Schmidt, Hugo. Mind the gap: service transition and interface problems for patients with eating disorders. *The British Journal of Psychiatry* (2005) 187: 398-400

⁴⁰⁵ Royal College of Psychiatrists (2003) *The Mental Health of Students in Higher Education (Council Report CR112)*. London: Royal College of Psychiatrists.

⁴⁰⁶ Allyson McCollam, 'With Mental Health and wellbeing in mind', *Scottish Journal of Residential Child Care*, Vol 8, October 2009, page 3

⁴⁰⁷ Ibid

What key actions should be developed to ensure high quality support in relevant delivery settings for looked after children with mental health needs?

Specific action that is required to address the needs of looked after children with mental health requirements are as follows:

- Training on emotional and mental health needs for residential care workers and foster carers
- Accessible and confidential support for CYP
- Services should be flexible and accessible to reduce stigma around mental health services should be available in outreach settings or other formats
- Explicit arrangements within each CAMHS team including referral protocols and care plan reviews
- Liaison between CAMHS and looked after children and young services, including multi agency planning and commissioning to develop and deliver mental health responses for looked after children and young

What needs to change practically?

Evidence from the Scottish Needs Assessment Programme (SNAP)⁴⁰⁸ which surveyed professionals working with CYP identified a number of key concerns among the residential care workforce- including lack of confidence and competence to deal with mental health issues. Other issues included the need for mental health services to be more flexible and to provide 'outreach support' to LAC outside of clinical, stigmatising settings.

Where children are looked after it is crucial that processes are put in place to ensure their health records are accurately recorded and updated so that should children change placements new carers are immediately aware of any ongoing or previous mental health issues.

All NHS boards should undertake to assess the physical and emotional and mental health needs of children who are looked after, and act with partners to ensure health services are more accessible to this group especially when they move into adulthood. There also needs to be capacity to support Children and Young People in settings that:

- Foster a consistent relationship
- Encourage permanence and maximise stability and continuity through crises
- Services need to be available and flexible
- Co-ordination of roles and responsibilities
- Active involvement of young people and their families - a stronger voice around Mental Health from CYP in care settings needs to be developed

⁴⁰⁸ Scottish Needs Assessment Programme.

[http://search1.scotland.gov.uk/Scotland?n=All&\\$rcexpanded=false&action=search&q=scottish+needs+assessment+programme+\(snap\)%3A+review+of+child+and+adolescent+mental+health+2003](http://search1.scotland.gov.uk/Scotland?n=All&$rcexpanded=false&action=search&q=scottish+needs+assessment+programme+(snap)%3A+review+of+child+and+adolescent+mental+health+2003) Accessed June 2013.

Short term and longer term solutions

The SNAP study also recommended that, in the longer term actions should be planned to support families facilitate early intervention and prevent family and placement breakdown and mental health responsibility should be mainstreamed into core work of child and family services.

In the short term actions need to be put in place following some of the models in Scotland to support the current looked after children and young population with mental health needs using existing service models and adapting where necessary to ensure:

- Raised awareness of mental health needs of looked after children and young
- Capacity in care settings to provide an environment that promotes mental health and wellbeing- including enabling carers to understand what lies behind presenting behavioural problems that are difficult to manage, for example looking at a children's early history, attachments, current relationships
- A bridge between CAMHS and care services
- Clear communications between care providers
- Informed strategic planning and developments

Examples of positive practice

- Staff training on mental health needs is delivered to care settings and built into core staff training
- Formal roles have been designated to enhance liaison between residential units and the local CAMHS
- Services work closely together to foster positive working relationships
- Findings suggest that dedicated mental health services for LAC can achieve:
 - Increased levels of awareness and confidence amongst care staff
 - More attention is given to the mental health needs of this population
 - More of this group are able to access to assessment and support for mental health needs
 - Services can make a significant contribution.
- An inverted triangle of actions is detailed and includes training, liaising, direct work, and screening.

Transition and aftercare

For this group good transition and aftercare arrangements are vital as many children leaving the care system into independence may not have networks of support available to them outside of the care system, thus increasing susceptibility to mental health difficulties at this testing time substantially and services commissioned need to ensure this group is not overlooked and flexible and relevant care provided during this time.

Young People in the Youth Justice System

Young people in the youth justice system have the same rights as all children and young people as enshrined in current UK law and policy and UN conventions which includes access to services that support their emotional health and well being. The UN Children's Commissioner commissioned a review of mental health services for young people in the youth justice system the findings of which suggest there are deficiencies in the current system which need to be addressed by mental health commissioners and partner organisations.

One such finding relates to transition between services which includes a lack of support on leaving custody and on transfer to adult services.⁴⁰⁹ The report recommends that the YOT mental health professional attend pre release sentence review meetings in order that they can ensure timely support from specialist services for those with mental health issues or complex needs if identified in the release plan.⁴¹⁰

Key report findings

The following part of the report details the findings and recommendations from a number of influential reports, conducted and/or commissioned by leading bodies such as the Royal College of Psychiatrists.

- 1) *Transition through mental health services: Working at the CAMHS/Adult Interface: Good Practice Guidance (Royal College of Psychiatrists 2008)*

The evidence suggests young people with mental health difficulties are at increased risk as they reach adulthood and become independence. This time of life is difficult for all young people so the addition of mental health needs enhances this period of difficulty. Added to this a transition from CAMHS to adult services, which often have different eligibility criteria and a new set of professionals, the service itself could increase mental health difficulties in young people.

There is a high risk that young people with moderate mental health needs will not be eligible for Adult Mental Health provision and could become lost at this point, with no support until later in life when they present with a more severe mental health need, which, with relevant preventative services in place at transition could have been managed.

What needs to change?

The report highlighted a number of areas for change. The need for provision of developmentally appropriate mental health services to those over 16 years and planned arrangements for transition of care from child to adult services for young people with a range of mental health problems was recommended. A number of risk factors were also identified for adolescents in transition, including becoming lost in the system and ensuring attendance, with a number of protective factors promoting effective transitions. These include ensuring one trusted adult taking on the key role of transition or link worker and being the sole point of contact for the young person experiencing transition

⁴⁰⁹ Sue Berelowitz, June 2011, 'I think I must have been born bad' Emotional wellbeing and mental health of children and young people in the youth justice system, 12.

⁴¹⁰ Sue Berelowitz, June 2011, 'I think I must have been born bad' Emotional wellbeing and mental health of children and young people in the youth justice system, 15.

'... you need one specific person who will stick with you and not lots of different people who will just pass you ion the whole time'

Quote from young person - pushed into the Shadows, 2007

Models of service:

The research recommends any of the following transition services:

- Designated transition service
- Designated transition team within a service
- Designated staff trained in adolescent work seconded to adult teams

In some areas there are fully funded community based multi-disciplinary teams designed to meet and work jointly with CAMHS and Adult Mental Health to meet the generic health needs of older adolescents and young adults. Good practice within these teams is to provide a youth centred flexible response to mental health needs.

Some NHS trusts have joined with other agencies to implement multi-agency commissioning for transition mental health teams solely for LAC. A number of NHS trusts also have designated transition or liaison posts, for example community psychiatrists with experience of working with adolescents. Virtual teams are another way to link CAMHS and adult teams.

2) Workforce and capacity for mental health transition teams – staffing requirements (Royal College of Psychiatrists)

There's an urgent need to quantify and design services appropriate for 16 and 17 year olds, and workforce and capacity requirements for specialist CAMHS working with 16 and 17 year olds can be found via Kelvin (2007) producing a staff tariff for a team serving a general population of 100,000 (approx. 2222 16 and 17 year olds), and establishes difference in staff requirements for teaching and non-teaching centres⁴¹¹.

For a comprehensive tier 3 CAMHS service for 0-18th birthday (not including YOT and substance misuse work) serving a general population of 100,000, based on Kelvin's calculations the service would need 19.3 working time equivalents for a non-teaching centre and 24.2 for a teaching centre. The paper recommends specific agreement and protocols between CAMHS and adult services regarding transfer of care for CYP receiving mental health treatment who fall within the following groups:

- ADHS
- ASD
- Emerging borderline personality disorder
- Mild to moderate LD
- Psychological sequale of chronic physical illness
- Psychological sequale of abusive experiences

This is important as some of these groups may not meet adult mental health eligibility criteria and transition protocols are ensure planning meetings at an early stage. No young person should be admitted to adult inpatient units, and all steps possible should be taken to ensure young people are admitted to age appropriate facilities. Where 16/17 year olds receive

⁴¹¹ http://www.rcpsych.ac.uk/pdf/Transition_2008.pdf. Accessed June 2013.

treatment in the independent sector professionals involved need to ensure transition arrangements are addressed as in the NHS.

Development needs of adolescents with severe mental disorders must be balanced with the needs for appropriate expertise in the professionals caring for them. The paper concludes that psychiatrists have an important role in working with their multidisciplinary colleagues to combine specialist skills and experience to develop appropriate mental health services to young people at transition stage. In addition to collaboration between child and adult services, they can facilitate effective engagement with adult psychiatric services or alternative appropriate services such as clinical psychology or young people's counselling services.

3) *Lost In Transition - moving young people between child and adult mental health services*
(Royal College of Nursing, 2007)

A study by the Royal College of Nursing stated that local services need to work together with the young people and their families in order to plan for effective transition. This includes working with mental health services where necessary. In order to engage young in their services, services must be flexible and accessible - online information and drop-ins should be considered. Where young people are disengaged and have no ownership there is a risk that they will 'drop out' when they reach adult services⁴¹².

The report also states that the voluntary sector should be utilised as a possible local service provider. Protocols and processes need to be clearly outlined and agreed between agencies, as a genuine shared arrangement to ensure that transition is as seamless as possible for a young person. Designated staff within specialities should also be available to handle transitions and built into job roles to ensure resource is available, and all staff should receive training about transition and the needs of the young adults.

Staff in adult and children's services need to be aware of the anxiety of the both the YP and often their parent/carers at transition stage. Communication about transition and the future needs to happen with the parents and with the young people, and issues of confidentiality need to be considered at this point as the child moves to adulthood. Where parents/carers and/or the young people feels disengaged there is a risk of them dropping out of the adult services, leading to a risk of more severe mental health problems in the longer term.

Finally the report stated that young people not only need to understand transition, but they need to be actively involved in designing their plans.

4) *Process outcome and experience of transition from child to adult mental healthcare: multi perspective study* (British Journal of Psychiatry, 2010)

The research conducted by Singh *et al.* evaluated the process outcomes and user care experienced of transition from CAMHS to AMHS for ADHD sufferers in Sheffield. A transition clinic has been running once a month, and this gives an opportunity for young people to

⁴¹² http://www.rcn.org.uk/_data/assets/pdf_file/0010/157879/003227.pdf. Accessed June 2013.

meet with AMHS staff to learn about ADHD in adults and how adult services are organised in Sheffield⁴¹³.

The clinic involve multiagency staff including from CAMHS. Following the meeting baseline data is entered onto the Trust Record system and a care plan devised. The clinic is available to allay anxieties that young people may have about AHS and aims to reduce the frequency of unattended appointments.

Views of young people who may attend the clinic were not sought at the initial project design phase but were collected on an ongoing basis. Some young people felt unable to attend the clinic, either due to a fear of mixing with others or due to wider disengagement. Where possible these young people were offered limited one to one sessions. Feedback from the young people and their parents/carers who attended the clinic was positive including that they:

- Understood the purpose of the meeting
- Thought it was useful to have a joint meetings
- Felt relevant areas were discussed
- Found the leaflet and information about the transition group useful
- Felt the meeting meant it would be easier to cope with the transfer to adult services
- Did not find it too much to have a large group meeting

5) *Planning mental health services for young adults- improving transition – a guide for commissioners (National Mental Health Development Unit 2011/12)*

A recent paper outlines the evidence base in relation to the Health and Social Care bill as well as policies from the previous government which are retained. It also highlights the importance of planning for personalised budgets when commissioning services. It recognises that in recent years there has been much improvement in mental health services but that transition is still a challenging areas which needs more work⁴¹⁴.

The Health and Social Care bill sets out that GP consortia will take on commissioning of mental health services, and need to build and maintain partnerships with various organisations and bodies to do so, including LAs, Schools, Health Watch, User groups, Third Sector.

The paper cites Sir Ian Kennedy's report *Getting it Right for Children and Young People* which emphasises that divisions of funds should not be allowed to interrupt what should be a seamless process for young people transitioning. The paper also points to participation tools that can be used by services with young people to involve them in commissioning and planning health services⁴¹⁵.

⁴¹³ Singh, et al. Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study. *The British Journal of Psychiatry* (2010) 197: 305-312

⁴¹⁴ <http://www.nmhd.org.uk/silo/files/planning-mental-health-services-for-young-adults--improving-transition.pdf>. Accessed June 2013.

⁴¹⁵ www.puzzledout.com

<http://yourewelcome.dh.gov.uk/Assess/Default.aspx>

The paper also finds that:

- Some services have taken a more holistic approach to the age of the young person – there are services which can be accessed up to 25 by those young people whose mental health and age development so requires.
- Early intervention and preventative services have been evidenced to save money in the long term, and these should be considered as a wider part of mental health commissioning.
- Commissioners need to look to their JSNAs to provide local evidence around their population when planning transition and mental health services. Commissioners are asked to ensure that the JSNA addresses transition, and if not, why not. Other key questions would be to track young people leaving CAMHS to establish their journey.
- Commissioners need to ensure patient satisfaction audits are built into contracts to ensure user feedback on services accessed.
- Designated link workers and shared transition protocols, alongside flexible approaches and promoting effective engagement for young people are consistent elements of successful services.

City and Hackney CAMHS Extended Service is cited as a good practice example.

6) *Young Minds: Transition in Mental Health Care (2010) (National Health Development Unit)*

The guide for professionals outlines difficulties of the transition process particularly in relation to young people with mental health requirements. The literature emphasises the importance of recognising that young people with mental health needs will also have a range of other needs: education, housing, welfare. Where young people have SEN their requirements will be higher and transition planning needs to start as early as possible⁴¹⁶.

The guide points to the *Healthy Lives Healthy People* White Paper⁴¹⁷ and highlights the need for age appropriate services in transition. The *No Health without Mental Health Strategy* (2011)⁴¹⁸ supports careful planning of the transfer of care between services, by planning for transition early, listening to young people and improving their self efficacy.

Where young people have autism then transitions in mental health need to take consideration of the Implementing and Fulfilling Rewarding Lives Statutory guidance for local authorities, specifically around ensuring that all relevant professionals, including SENCOs are involved in transition planning and that the young person and their parent/carer are informed of their right to a community care assessment and the right of their carer to a carer's assessment. Where individuals do not fulfil referral criteria for adult mental health teams, the guidance advises that it is good practice to signpost on to other sources of support and information available locally and nationally.

⁴¹⁶ <http://www.nmhd.org.uk/silo/files/transitions-in-mental-health-care.pdf>. Accessed June 2013.

⁴¹⁷ <http://www.official-documents.gov.uk/document/cm79/7985/7985.pdf>. Accessed June 2013.

⁴¹⁸ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/135457/dh_124058.pdf. Accessed June 2013.

The Young Minds report identified information sharing as a potential barrier to transition. To overcome this barrier it recommended that from the start of the process agencies should work with the young person and their family to ensure that with their permission, the relevant information can be shared across agencies to enable services to build up an accurate and complete picture of the needs and circumstances of the young person. The guidance also highlights practical ways in which to ensure young people can be engaged with transition planning, for example the type of paper work used.

Finally, it stressed the importance of not overloading young people with assessments and reviews. And that practitioners need to be clear about which approach to use in a given situation with a young person and how the CAF would capture issues about the psychological wellbeing if CYP not subject to the Care Planning Approach (CPA).

7) *Synthesis and conceptual analysis of the SDO Programme's research on continuity of care (Report for the National Institute for Health Research Service Delivery and Organisation programme, 2009)*⁴¹⁹

This report focuses on continuity of care using studies and scoping studies. The literature does not focus on young people specifically but useful best practice around providing continuity of care can be gleaned from the report's findings. The report highlights concern about continuity of care within service systems has been a consistent feature of evaluative research in both health and social care. Some of the factors identified as playing a part in the delivery (or not) of continuity of care for service-users and their families or carers are:

- Communication between primary and secondary health care and between long-term and short-term care systems;
- Team working within single sectors;
- Professional boundaries;
- Systems for transition between different types of services; and
- Care pathways for individual service users.⁴²⁰

The Parker report (2010)⁴²¹ advised that a minimum definition of continuity of care should include the following elements:

- The experience of a co-ordinated and smooth progression of care from the service users' point of view (experienced continuity);
- Perspectives on both the process and/or outcomes of continuity of care are important to consider.
- Continuity of care is something that is experienced by patients and carers. Hence, their views need to be examined to establish how they define and value it, whether services satisfy these requirements, and what impact continuity (or lack of it) has on patients and their families.

⁴¹⁹ Parker, G., Corden, A. and Heaton, J. (2010) *Synthesis and Conceptual Analysis of the SDO's Programme's Research on Continuity of Care*, National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre, Southampton, <http://www.york.ac.uk/inst/spru/research/pdf/Continuity.pdf>

⁴²⁰ Parker, G., Corden, A. and Heaton, J. (2010) *Synthesis and Conceptual Analysis of the SDO's Programme's Research on Continuity of Care*, National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre, Southampton, <http://www.york.ac.uk/inst/spru/research/pdf/Continuity.pdf>

⁴²¹ Ibid

Another core claim of the SDO scoping report is that continuity of care is a complex, multi-dimensional, concept. The achievement of good continuity from the patients' perspective largely depends on services doing well on these dimensions (depending on which are important to individual patients and carers).

Scoping report findings

In the original scoping report attached to the *Synthesis and conceptual analysis of the SDO Programme's research on continuity of care*, Freeman *et al* (2001)⁴²² acknowledge the language gap between professionals, who are accustomed to the phrase 'continuity of care', and patients and carers, for whom the phrase may not be familiar. Service users were heavily involved in the scoping and main studies. Mental health service users talked from experience of transitions between teams of professionals in the context of their moving home or being discharged, but also because of team restructuring (severe mental illness). In this study, people who had complex or problematic experiences of continuity said that transitions could be stressful and drawn-out, with ineffective communication between teams of professionals. Change of psychiatrists was common. Transition at discharge was a key point of vulnerability, for example moving from a strict routine to coping alone and supportive transitions, personalised and situated in daily life, contributed to good continuity (severe mental illness). Although some mental health service users had experience of poor communication between different parts of the service, this was not true for everyone.

The scoping report also found that patients who would have preferred personal continuity but experienced discontinuity had negative views about too much change. For mental health service users, changes in personnel also meant negative outcomes associated with having to retell their story. Experiencing team changes among staff, as well as being stressful for service users, led to communication gaps.

For mental health services users also, inconsistency in provider could lead to some lack of consistency in treatment, which could also be felt as a lack of professional commitment, for example when a new professional was not supportive of the care set in place by a predecessor (severe mental illness).

Personal continuity with professionals

From both the primary care and the mental health studies within the SDO Report both studies there were some findings that personal continuity with professionals was not always experienced as helpful. A view from one carer in the primary care study was that the GP whom her husband always consulted did not see beyond the disease. For mental health service users, a change in relationships with professionals could be helpful if the previous relationship was poor (severe mental illness).

Recognition by professionals of carers' own needs for support, and responsive provision of help was important to carers in the diabetes, cancer and severe mental illness studies. In the diabetes study, carers mentioned their own mental health needs in their supporting role, and

⁴²² Freeman G, Shepperd S, Robinson I, Ehrich K, and Richards S. 2001.

would have liked some help here. Some wanted, but had not found, access to social support (diabetes). Close persons in the cancer study described their own strong emotional responses to diagnoses and delays in the patient's treatment, and becoming aware of and having to deal with changes in family dynamics and relationships.

Carers of mental health service users said that when services responded to crises rather than providing preventative support to mental health service users, then they too could feel invisible, and feel that their support had been withdrawn (severe mental illness).

Some carers of mental health service users had found carer support groups helpful (severe mental illness).

Co-location of services

A clear theme in the studies within the SDO report was to have professionals overlapping, co-located, and fostering long term good relationships. However, the issue of where a multi disciplinary service is located is often debated. For instance if all teams are located in a clinical setting then outreach into the community will be more difficult (p.66)⁴²³. Sometimes virtual boundaries may be more effective and contact between professionals was needed as well as co-location in order to have a real impact on continuity of care. Within this team leaders and strong management are also vital.

Data sharing and communication

Communication, of itself, was seen as key, and good quality record keeping was a part of that. However, informal information sharing was also important, facilitated by professional links and relationships. The geography or settings of services may have influenced this. Professionals clearly valued co-location and proximity, though it was less clear that they had a demonstrable impact on continuity for service users. Further, when co-location was not possible, systems could be put in place to transcend geography: co-location and proximity is thus not a *sine qua non* of continuity.

8) NICE Mental Health Guidance (2011)

The NICE guidance states that primary and secondary care clinicians, managers and commissioners should collaborate to develop local care pathways that promote access to services for people with common mental health disorders by:

- Supporting the integrated delivery of services across primary and secondary care;
- Having clear and explicit criteria for entry to the service;
- Focusing on entry and not exclusion criteria;
- Having multiple means (including self-referral) to access the service; and
- Providing multiple points of access that facilitate links with the wider healthcare system and community in which the service is located.

⁴²³ Parker, G., Corden, A. and Heaton, J. (2010) *Synthesis and Conceptual Analysis of the SDO's Programme's Research on Continuity of Care*, National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre, Southampton, <http://www.york.ac.uk/inst/spru/research/pdf/Continuity.pdf>

The guidance also recommended that primary and secondary clinicians, managers and commissioners should work together to ensure:

- Most effective early intervention is taken
- Least intrusive experience by the user
- Establish clear links between other services
- Information about the care pathways and processes is shared with and understood by with the service user and their carer

Finally, a stepped-care model should be used to organise the provision of services and to help people with common mental health disorders, their families, carers and healthcare professionals to choose the most effective interventions.

Conclusions/recommendation

- *Cost effectiveness:* Of the literature reviewed, cost effectiveness can be achieved by combining or moving resources. For example although additional resource may be required to set up and run on a service such as a drop in clinic to engage young people, this should see savings elsewhere with better take up of appointments and even reduced need for more specialist services. Cost effectiveness also needs to be considered in relation to the move towards personalised budgets in children's services, and any contract should be flexible to build in a move away from purchasing block places. Early intervention provision in universal or targeted services again can save money in the longer term by reducing a need for specialist high cost services, and again this should be considered by commissioners at the start of planning for services. Combining commissioning with additional NHS trusts can lead to savings and this is another option that could be explored.
- *Family and carers:* The literature reviewed focused on the child's mental health rather than the parent's. However it was highlighted that services need to engage clearly and positively with parent carers where young people are reaching transition to help them understand the process but also to help them come to terms with the fact that their young person will become an adult, and as such some matters will become confidential between the service and the young person. Parent/Carers often struggle to understand this and can lead to them disengaging from adult services leading to worsening mental health in their young person.

By involving parents in transition (although by being clear that the young person will design their care plan, not the parent) through mechanisms such as drop in sessions with children and adult services staff, parent/carers can come to terms with the changes and understand a shifting of roles as the young person becomes an adult. Allowing parents to meet other parent/carers of young people can be immensely helpful for them as it provides a peer group of others going through a similar experience.

Where young people with mental health needs are looked after the literature makes it very clear that specific support and consideration for this group should be in place and this includes ensuring that age appropriate and flexible care is available for young people based in residential care settings which is offered in addition to clinical support⁴²⁴.

⁴²⁴ 'With Mental Health and Wellbeing in Mind' Scottish Journal of Residential Childcare (2009)

- *Early intervention:* The literature highlights the importance of flexible, accessible, age appropriate support for young people with mental health needs. In terms of early intervention, some of the more recent literature highlights the evidence base for this, and again the cost associated with early intervention measures should be impetus for commissioners to consider early intervention programmes as a key element of any mental health offer. Information, communication and ownership are key.
- *Stigma:* Providing mental health services in clinical settings stigmatises them to young people. The literature outlines other ways to deliver services, such as in community settings or, for instance with looked after children, by undertaking outreach work, to ensure that young people do access the support they need. More understanding about mental health generally is needed and the literature gives a helpful reminder of some key facts about mental illness.⁴²⁵

The literature asserts that staff in residential care settings, as well as staff in universal settings such as schools, require varying levels of training to ensure that they are better informed on mental health and more confident around young people who may display mental health needs.

Transition from child to adulthood is a challenging time for all young people. For young people with mental health needs where they will be moved to new services, or maybe not even meet the threshold of those services, this time is exacerbated, and for those young people in the care system with mental health requirements the challenge is greater still. Therefore the period of transition for young people with mental health needs must be a key component of any mental health strategy and be clearly provided for within commissioned services.

Key recommendations from the literature for effective transition are summarised as:

- The need for shared and clear transition protocols
- A Designated transition team
- A JSNA that highlights transition
- Services which can be accessed more flexibly (eg up to 25 where a young person's psychological development means that to move them to adult services at 18 would not be appropriate)
- Involvement with the young person around designing their plan
- Clear and on-going communication with parent/carers
- Multi agency transition teams, either housed together or virtual, with transition built into job descriptions
- A system that allows people and parent/carers to meet with adult services staff and understand adult services before they turn 18

⁴²⁵ *Planning mental health services for young adults- improving transition – a guide for commissioners* (National Mental Health Development Unit 2011/12)

- Training for staff in CAMHS and AMHS around the different elements of each other's services and criteria with core training on mental health built into core training requirements across services⁴²⁶
 - Strong working relationships, communication and shared responsibility around the transition process
 - Relevant, accessible information about transition for parent/carers, professionals (e.g. schools, care settings) and young people
 - Ensuring that specific groups transitioning through services (care leavers, young offenders, young people with disabilities) are specifically catered for within any mental health strategy
- *Continuity of Care:* For young people with mental health needs is explored through the report Synthesis and conceptual analysis of the SDO Programme's research on continuity of care, and outlines the need for primary and secondary care practitioners to work together virtually, in a co-located environment or through enhanced communication. However the patient experience is where the measure of working together will be best assessed. This ties in with the recognition that language across services and sectors, which can be a barrier when trying to ensure closer working between services.⁴²⁷

⁴²⁶ Lost In Transition- moving young people between child and adult mental health services (Royal College of Nursing, 2007)

⁴²⁷ See also NICE clinical guidance (2011)

USER INVOLVEMENT: A REVIEW OF THE LITERATURE

Scope

This paper reports the findings of a review conducted to answer four questions in relation to user involvement:

8. What does the evidence say are the most effective practically focussed mechanisms that commissioners and clinical and non-clinical providers can take to ensure that service users are involved in (a) commissioning and monitoring of services and (b) the design of their own care arrangements?
9. What does the evidence say about the effectiveness of peer support interventions?
10. What does the evidence say about which mental health services are most effectively provided in the third sector?
11. What does the evidence say about approaches to balancing investment into prevention against care services?

This paper provides a high level but pragmatic overview of the available evidence on the contribution user involvement in the development of services, at the macro and micro levels, can make to the wellbeing of people with mental health needs. Due to resource and time constraints it was not possible to offer a full systematic appraisal of all available evidence which restricts the degree to which any findings and conclusions can be extrapolated from. However some hopefully, useful insights are provided.

Introduction

In many countries, service user involvement in the planning and provision of mental health services has been growing over the last two decades, especially in areas where institutional service provision has been changed to a community-orientated model of care⁴²⁸. However, despite a plethora of policy reforms and pockets of good practice, user involvement in mental health still needs to be built-on and improved⁴²⁹. This review explores the policy initiatives and reviews the evidence for successful user involvement.

Methods

The methodology employed by this paper takes as its starting point the acceptance of the importance of service users' involvement in the development and provision of services and takes as its objective an examination of the literature's commentary about the quality of involvement offered, how this can be improved and related good practice issues. Therefore, discussion commences by considering the policy context in which service user involvement has grown before moving on to contrast involvement in theory and practice. Subsequently, the importance user led services will be outlined and a series of good practice issues will be discussed, including what is meant by '*involvement*,' before ending with a statement of conclusions reached and of their associated implications.

⁴²⁸ Chamberlain J. (2005). User/consumer involvement in mental health service delivery. *Epidemiologia e Psichiatria Sociale* 14, 10-14.

⁴²⁹ Lynda Tait & Helen Lester. Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment* (2005), vol. 11, 168-175

Defining a 'Mental Health Service User'

Before proceeding it is important to be clear about what is meant by *'mental health service users'* or *'someone with mental health needs'*. This is a possible source of confusion since, according to Tait and Lester (2005),⁴³⁰ the language used to describe these people is more varied than in any other sector of health and social care. Traditionally they have been portrayed as patients - as objects of the clinical gaze⁴³¹ but, more recently, they have also come to be regarded *'consumers'*, *'survivors'* and *'providers'* all of which imply different notions of the roles and responsibilities held by people with mental health needs.

Tait and Lester point out that while users are increasingly seen as *'consumers'* (i.e. *'customers'*) who can exercise *'informed'* choice the force of this empowering concept is diluted by a public focus on, and a political concern with the risks the mentally-ill present to society. As a result risk management and the safety of the general public has impeded the development of consumer rights within mental health.

The notion of the user as a *'survivor'* developed rapidly in the 1980s and 1990s⁴³² and offers a positive image of people with mental health needs as individuals who have the strength to survive the mental health system. This conceptualisation of service users has underpinned the development of user-led services:

"The movement...needs to remain independent in order to offer critical comment on services and to provide alternative sources of support and information, while being strong enough to have a real impact on mainstream service delivery for those with severe and long-term problems." (p.1)

The identification of service users as *'providers'* is reflected in the development of user-led services which are found across the statutory and voluntary sectors throughout the country. In Tower Hamlets the Borough Council and its NHS partners jointly commission a range of successful services provided by user led organisations. This has bolstered the strongly and positively correlated definitions of users as *'consumers'* and *'survivors'* which, in turn, supports their definition as *'providers'*.

In short what emerges from the debate about the definition of mental health service users is that they cannot simply be described as patients or as any one *'thing'*. They sit at the centre of a, figurative, Venn diagram and can be regarded as *'consumers'* and *'survivors'* and *'providers'* and (sometimes) *'patients'*. The definition is multifaceted and dynamic.

Findings

The questions detailed above were not answered in this review. Instead a synopsis of the policy context, the theory behind user involvement and benefits are detailed in this review.

⁴³⁰ Tait L. and Lester H. (2005, 11 168-175), *"Encouraging User Involvement"*, Mental Health Services, Royal College of Psychiatry.

⁴³¹ Pilgrim D. and Rogers A. (1999), *"A Sociology Of Mental Health And Illness"*, Buckingham: Oxford University Press.

⁴³² See Wallcraft J. With Read J. And Sweeney A. (2003), *"On Our Own Terms: Users And Survivors Of Mental Health Services Working Together For Change"*, The Sainsbury Centre for Mental Health

The Policy Context

*“If the fundamental purpose of the Government’s proposed changes to the NHS – putting the patient first – is to be made a reality, the system that emerges must be grounded in systematic patient involvement to the extent that shared decision making is the norm.”*⁴³³

In policy terms, there is nothing new about the drive to make mental health services more user led. Since the establishment of Community Health Councils in 1973, the rhetoric of generic user involvement has become a core component of NHS policy. In 1989, the NHS and Community Care Act was the first piece of UK legislation to establish a formal requirement for user involvement in service planning. Subsequent key policies in the early 1990s include the Patient’s Charter⁴³⁴ and plans set out in Local Voices⁴³⁵, which aimed to make services more responsive to patients’ needs. However, this was limited by stressing consumerism rather than partnership or participation.

In 1997 a central tenant of the New Labour NHS Modernisation agenda was *‘patient and public involvement’* which was enshrined in the *NHS Plan*⁴³⁶ that emphasised the Government’s commitment to creating a patient-centred NHS. The *NHS Plan* proposed the development of the Patient Advice and Liaison Service (PALS). Also, Section 11 of the *Health and Social Care Act 2001* required all NHS organisations to engage with users in service planning and evaluation as well as providing opportunities for treatment decision making.

User involvement in the specific context of mental health was encouraged in documents such as *The Health of the Nation*⁴³⁷, *Working in Partnership*⁴³⁸ and *Building Bridges*⁴³⁹. Indeed, *Working in Partnership* declared:

“The work of mental health nurses rests upon the relationship they have with people who use services. Our recommendations for future action start and finish with this relationship.” (p. 5)

Following on from the White Paper *Our Health, Our Care, Our Say* (2006)⁴⁴⁰ and the Darzi review of the NHS⁴⁴¹, the 2012 *Health and Social Care Act*⁴⁴² sought to reinforce patient involvement and control over their own care and states the Government’s aim: *“no decision about me, without me”*⁴⁴³. To this end the Act, as indicated above, introduced a number of key legislative changes to strengthen the collective voice of people with mental health needs. These included:

- Imposing on the NHS Commissioning Board, Clinical Commissioning Groups, Monitor and Health and Wellbeing Boards duties with regards to involvement of patients, carers and the public. Commissioning Groups will have to consult the public

⁴³³ NHS Future Forum Patient Involvement and Public Accountability Report (June 2011)

⁴³⁴ Department of Health (1991d) *The Patients Charter*. DOH London.

⁴³⁵ Department of Health (2002). *Local Voices: the Views of the People in Purchasing*. London. NHS Management Executive.

⁴³⁶ Department of Health (1st July 2000). *The NHS Plan: a plan for investment, a plan for reform*. Accessed at: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4002960 Accessed July 2013

⁴³⁷ Department of Health (1992). *Health of the Nation*. London

⁴³⁸ Department of Health (1994). *Working in Partnership*. London

⁴³⁹ Department of Health (1995). *Building Bridges*. London

⁴⁴⁰ Department of Health (2006). *Our Health, Our Care, Our Say*. Accessed at: <http://www.official-documents.gov.uk/document/cm67/6737/6737.pdf> Accessed July 2013

⁴⁴¹ Department of Health (2008). *High Quality Care for All*. Accessed at: <http://www.official-documents.gov.uk/document/cm74/7432/7432.pdf> Accessed July 2013

⁴⁴² Accessed at: <https://www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets>. July 2013.

⁴⁴³ <http://www.dh.gov.uk/health/files/2012/06/B3.-Factsheet-Greater-Voice-For-Patients-300512.pdf>

on their annual commissioning plans and involve them in any changes that affect patient services⁴⁴⁴.

- The establishment of Healthwatch as a statutory committee of the Care Quality Commission and as a new national body representing the views of users of health and social care services, other members of the public and Local Healthwatch organisations. It will advise and provide information to the Secretary of State, the NHS Commissioning Board, Monitor, English local authorities and the Care Quality Commission on the views of users of health and social care services and their experience of such services. Local Healthwatch organisations will also help ensure that the views and feedback from patients and carers are an integral part of local commissioning across health and social care. Their activities will also include providing information about local care services and choices to be made in respect of those services.

Within mental health the development of the cross Government mental health strategy, *'No Health Without Mental Health'*⁴⁴⁵ has run in parallel with the development of the Health and Social Care Act. Like the latter, the former stresses the importance of choice and control for patients. A guiding principle of the strategy is a commitment to providing people with control over their lives which it regards as being associated with better physical and mental health. It is a commitment that means:

"...ensuring that people with mental health problems are able to plan their own route to recovery, supported by professional staff who help them identify and achieve the outcomes that matter to them, including a suitable and stable place to live, educational opportunities, jobs and social contact; and put them, and their families and carers, at the centre of their care by listening to what they want, giving them information, involving them in planning and decision-making, treating them with dignity and respect, and enabling them to have choice and control over their lives and the services they receive". (p. 16)⁴⁴⁶

The ideas contained within *No Health Without Mental Health* are transformational, in so far as people with mental health needs are given a leadership with respect to the services they receive. It is a shift which chimes to the vision for adult social care as articulated in *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care* (2007)⁴⁴⁷.

User involvement: In theory and practice

User involvement encompasses a range of different ideas, as does the concept of *user*⁴⁴⁸. At a micro level it concerns the active participation of individuals in the formulation of their own support packages while at a macro level involvement is about the participation of those who use services in service level planning, evaluation and, increasingly, in the training and research arenas. Peck *et al.* (2002)⁴⁴⁹ constructed a matrix which combines three distinct conceptions of users' involvement – as recipients, subjects of consultation and agents in

⁴⁴⁴ Health and Social Care Act (2012), Chapter 7, Part 1, 13H and 14U.

⁴⁴⁵ Centre for Mental Health, Department of Health, Mind, NHS Confederation Mental Health Network, Rethink Mental Illness, Turning Point (24 July 2012). No Health without Mental Health. Accessed at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/156084/No-Health-Without-Mental-Health-Implementation-Framework-Report-accessible-version.pdf. July 2013.

⁴⁴⁶ Ibid

⁴⁴⁷ Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care (2007).

⁴⁴⁸ Braye, S. (2000), "Participation And Involvement In Social Care: An Overview", in "User Involvement And Participation In Social Care: Research Informing Practice" (eds H. Kemshall & R. Littlechild), pp. 9–28. London: Jessica Kingsley.

⁴⁴⁹ Peck, E., Gulliver, P. & Towell, D. (2002) Information, Consultation or Control. User Involvement in Mental Health Services in England at the Turn of the Century. *Journal of Mental Health*, **11**, 441–451.

control - with their involvement within mental health services. This is describes as operating at four levels:

1. Interaction between service users and in the form of self-help;
2. Interaction between individual users and professionals working with them;
3. Management of local services; and
4. Planning of overall services.

The different conceptions of service user involvement and different level of interaction allows the matrix shown in table 1 to be constructed. Peck *et al.* suggest this illustrates the sheer diversity of mental health service user involvement but also indicates that many initiatives are clustered in the consultation category, with the ‘agent in control of the overall service planning’ cell empty. This points to the challenge of securing users involvement at the strategic (i.e. macro) level.

Table 1. _____ Examples of user involvement

	<i>Conceptions of user involvement</i>		
<i>Levels of interaction</i>	Recipient of communication	Subject of consultation	Agent in control
Between service users	<ul style="list-style-type: none"> • Newsletters • Periodicals 	<ul style="list-style-type: none"> • Advocacy schemes 	<ul style="list-style-type: none"> • Hearing voices • Periodicals • Newsletters • Periodicals
Between service users and professionals	<ul style="list-style-type: none"> • Receiving care plans 	<ul style="list-style-type: none"> • Agreeing care plans 	<ul style="list-style-type: none"> • Direct Payments/Personal Budgets
Management of local services	<ul style="list-style-type: none"> • Receiving information services 	<ul style="list-style-type: none"> • Patient councils • User surveys • User-focused monitoring 	<ul style="list-style-type: none"> • User-run crisis houses • Social firms
Planning of overall services	<ul style="list-style-type: none"> • Community care plans 	<ul style="list-style-type: none"> • Mental health taskforce membership • Stakeholder conferences • Users on local implementation teams 	

Of course, the work carried out by Peck and his colleagues is now dated and there has been a sustained push, as is evidenced by the raft of policy initiatives referred to above, to make user led mental health services a reality at the strategic level. A recent survey by the CQC⁴⁵⁰ indicates that initiatives are having a beneficial effect with a majority of 15,000 users of community mental health services expressing satisfaction with these services.

However, there is also evidence that services users, especially those from the black and minority ethnic communities, continue to have limited opportunities to influence change. It seems that there remains a gap between the theory and practice of user involvement. This risk is particularly grave when the importance of service users’ involvement is considered, as

⁴⁵⁰ <http://www.cqc.org.uk/media/cqc-publishes-views-more-15000-people-using-community-mental-health-services>

detailed in the section below. The matrix provided by Peck provides a useful tool with which to monitor, manage and mitigate this risk.

The Importance of Service Users' Involvement

When commenting on the relevance and importance of service user involvement and user led services, the Sainsbury Centre for Mental Health⁴⁵¹ concludes that there are a range of benefits for both users and staff. These benefits include:

- For the service users:
 - Experience greater dignity and self-worth
 - Improved morale among service users and staff
- For the services per se:
 - A better understanding and acceptance of service users' perspectives
 - Service improvements resulting from the expert knowledge brought by service users to a partnership with providers and other stakeholders
 - Better decision making and better health outcomes
 - Increasing acceptability of changes
 - More likelihood of new initiatives succeeding
 - A better understanding of the context of people's live in the community
 - Helps makes service providers more accountable to the communities they serve

Similarly, Tait and Lester⁴⁵² observe that there are a number of inter-related reasons for believing that mental health service user involvement is more than a “*politically mandated good*” (p. 170)⁴⁵³ and is a worthwhile activity with a range of practical and ethical benefits. These include:

- *Users are experts about their own illness and need for care:* There is widespread recognition that service users are experts, with an in-depth knowledge of mental health services and of living with a mental health problem⁴⁵⁴. By definition, no one else, no matter how well trained or qualified, can possibly have had the same experience of the onset of mental illness, the same initial contact with services or the same journey through the mental health system. These experiences are an important resource that can help to improve individuals' packages of care as well as services generally. If mental health professionals can tap into this expertise, they make their own jobs much easier and more productive by focusing on users' considerable strengths.
- *Users may have different but equally important perspectives about their illness and care:* Service users and mental health professionals may have very different perspectives. The Sainsbury Centre (2010), for example, points out that service providers and commissioners may have divergent priorities and involving service users can provide insights that prompt commissioners to re-evaluate their plans, priorities and assumptions.

⁴⁵¹ Sainsbury Centre for Mental Health (February 2010), “*An Evaluation Of Mental Health Service User Involvement In The Recommissioning Of Day And Vocational Services*”, London: Sainsbury Centre for Mental Health

⁴⁵² Lynda Tait & Helen Lester. Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment* (2005), vol. 11, 168–175

⁴⁵³ Ibid

⁴⁵⁴ See <http://psychminded.co.uk/news/news2007/May07/serviceuser002.htm>

- *User involvement may increase the understanding of mental-illness: May (2001)*⁴⁵⁵ suggests that the inclusion of users' experiences and knowledge through service user involvement can challenge *a priori* assumptions about mental-illness and of the mentally-ill, thereby, increasing the understanding of both and mental health literacy (see above).
- *Users are able to develop alternative approaches to mental health and illness: MIND* while not endorsing alternative therapies and making clear that it does not regard them as a substitute for traditional treatment recognises that these therapies can be useful, while the Hearing Voices Network⁴⁵⁶ encourages positive working practices with people who hear voices and works to promote greater understanding and tolerance of this condition.
- *User involvement as at therapy: Involvement can be therapeutic.* Helping to shape service, particularly, when users work together can increase self-confidence, raise self-esteem and promotes the development of new skills. These are beliefs which are inherent in the recovery model.
- *User involvement may encourage greater social inclusion: People with mental health problems are among the most socially excluded within any society, subject to the interlocking and mutually compounding problems of impairment, discrimination, diminished social roles, unemployment and lack of social networks.*⁴⁵⁷ Therefore, encouraging greater user involvement, including paid activity, can be empowering and encourage greater social inclusion.

Markers of Effective Involvement

Following a review of the literature, the Sainsbury Centre⁴⁵⁸ concludes that there is a growing body of research evidence which has addressed the issue of good practice in user involvement and ways to evaluate that practice. Some of the findings that can be drawn from the research on involvement are:

Markers for effective involvement:

- Clarity about the aims and limits of involvement.
- Transparent support for principles that involvement to improve accountability, empower service users, improve public health and raise public perceptions of the quality of care that is provided.
- More involvement of front-line staff in managing change successfully.
- A perception of service users as more than consumers focused only on the details of service provision, but as citizens with a broader range of human and democratic rights.
- A core belief in service users as active partners – *even if the partnership is unequal.*
- Techniques of genuine involvement should be embedded, continuous and varied.
- Service users should be represented directly, collectively or via peer advocates.

⁴⁵⁵ May, R. (2001) "Crossing The 'Them And Us' Barriers: An Insider Perspective On User Involvement In Clinical Psychology", *Clinical Psychology Forum*, 150, pp.14–17.

⁴⁵⁶ <http://www.hearing-voices.org/>

⁴⁵⁷ See Morgan, C., Burns T., Fitzpatrick, R and Pinfold P. (2007) "Social Exclusion And Mental Health: Conceptual And Methodological Review", *British Journal of Psychiatry* 191 pp 477 - 483

⁴⁵⁸ Sainsbury Centre for Mental Health (February 2010), "An Evaluation Of Mental Health Service User Involvement In The Recommissioning Of Day And Vocational Services", London: Sainsbury Centre for Mental Health

- Accept and manage the conflict inherent in the involvement of service users in change.
- Regard mechanisms for involving users and carers as health technologies, with a rigorous approach taken to identifying aims, choosing and implementing an approach to achieve these aims, and monitoring to see if the aims have been achieved.
- All sectors, practitioners and users should plan for models of user involvement which are not tokenistic, undermining or damaging to self-esteem or wellbeing.

Markers for inadequate involvement:

- Lack of feedback – this has a negative effect on service user motivation, trust and confidence.
- Power relations need continuous attention - they can be a major cause of difficulties.
- Perceived risk that user involvement will be exploited to give appearance of democratising public services without allowing policy shifts in *undesirable* directions.
- Staff feel threatened by user involvement – involvement work best when front-line staff and other stakeholders are also meaningfully engaged.
- Information shortage – accessible information is fundamental to meaningful involvement and service user leadership.
- Costs of involvement –user involvement if properly implemented can be financially expensive and time-consuming for organisations and the service users themselves. Sufficient funding must be made available to take forward involvement and to cover the costs of participating service users.
- Representativeness – This concern is often expressed by professionals referring to those service users who are involved in the development of services and taking a leadership role in this activity as being the '*usual suspects*'. Interestingly, Lindow⁴⁵⁹ suggests that the problem of '*representativeness*' may be used as an unconscious method of resisting service user involvement.

Good Practice

The long campaign for greater service user involvement and leadership in mental health services has seen their rights and the public's (e.g. the State's) expectations in this regard consolidated across a range of statutes, guidance and reports. This is explicitly recognised and reflected in the NICE Quality Standard for service user experience in adult mental health⁴⁶⁰ which contains the following statements:

Statement 3. People using mental health services are actively involved in shared decision-making and supported in self-management;

Statement 5. People using mental health services feel confident that the views of service users are used to monitor and improve the performance of services; and

⁴⁵⁹ Lindow, V. (1999), "*Power, Lies And Injustice: The Exclusion of Service Users' Voices*", in "*Ethics and Community in the Health Care Professions*" (ed. Parker), pp. 154–177. London: Routledge

⁴⁶⁰ NICE Quality Standard for service user experience in adult mental health (QS14) (2011). <http://publications.nice.org.uk/quality-standard-for-service-user-experience-in-adult-mental-health-qs14/list-of-statements>

Statement 8. People using mental health services jointly develop a care plan with mental health and social care professionals, and are given a copy with an agreed date to review it.

Less prosaically, Tait and Lester⁴⁶¹ identify ways of embedding good practice that are not incentivised by regulation. For example:

Involving Service Users In Research Projects: Service users bring a unique perspective to research and can impose on it their own priorities which may differ from those of academics and health and social care professionals. Recognition of this has led to the development of a vibrant body of research some of which has been referred to in the course of this review e.g. Lindow (1999), Rose (2001), Deegan (1988,1993,1960), Rose (2001), Mind (2011)⁴⁶².

Staff Selection: Tait and Lester (op cit) contend that service users' involvement in staff selection is not just symbolic but improves the appointment process. They report that evaluations of users' involvement indicated that some participants in the selection exercise felt that:

"participants felt that questions from the service user were 'wise and thought-provoking'. In particular, the user was seen as being able to offer a human perspective that was well respected: 'She came up with questions none of us professionals would ever have thought of and got a much stronger sense of what the candidate was like as a person". (p.172)⁴⁶³

However, Sheldon and Harding (2010)⁴⁶⁴ point out that at its most fundamental level good practice in service user involvement should be a principled activity. They stress that:

- Involvement must be inclusive, equitable, supportive, respectful, transparent and open, acknowledging and valuing diversity.
- Involvement should aim to be service user-and carer-led with them, for example, determining research/consultation questions rather than simply responding to consultations.
- Involvement should acknowledge power differentials and participants should strive towards partnership with service users occupying a leadership role.
- Involvement should build links within and outside of the organisation(s) participating.
- Involvement should occur at every stage of an initiative.
- Involvement initiatives should be documented, evaluated and reflected upon so that learning is not lost with feedback on its impact being given at every stage.
- Involvement should be iterative and follow the *act – evaluate – reflect – learn-act* cycle.

⁴⁶¹ Lynda Tait & Helen Lester. Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment* (2005), vol. 11, 168–175

⁴⁶² Also see Armes D, Barrett J, Hindle D, Lemonsky F and Trite j (June 2011), *Mental Health Researchers' Toolkit for Involving Service Users in the Research Process*, National Institute for Health research.

⁴⁶³ Lynda Tait & Helen Lester. Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment* (2005), vol. 11, 168–175

⁴⁶⁴ Sheldon K and Harding E (May, 2010), *Good Practice Guidelines to Support the Involvement of Service Users and Carers in Clinical Psychology Services*, The British Psychological Society.

Within this framework of principles, Sheldon and Harding believe service user involvement should start small and grow to build confidence and build on success. Good practice also demands that service user involvement is supported by payments in return for the time given by them to involvement activities and to any related work they undertake while they must also be offered necessary training and support. At all times it is important to be sensitive and responsive to the needs of service users with users-friendly information and communication being and with meetings held at times in accessible places.

Finally, good practice revolves around clarity about what, precisely, is meant by '*involvement*'. Herein, service user and carer involvement is about the aspirational development of a relationship between individuals and professionals that takes the form of an equitable and inclusive partnership. The power differentials and expertise between these two groups may be unequal but the objective of involvement is for professionals to learn from the people they support with and to work towards decisions and changes that are as user-led as possible with mental health professionals utilising their training to provide a service that is '*on tap not on top*'⁴⁶⁵. This means that, at all times, the overarching goal of involvement should be the development of approaches that provide individuals with real choices, individually and collectively⁴⁶⁶.

Conclusions/Recommendations

- Failure to develop a definition of people who use mental health services may mask a misunderstanding of their support needs as individuals and as a group and lead to inaccurate labels being applied for the convenience of the labeller. This risks the development of approaches to *information* for and *communication* with people with mental health needs which are inappropriate.
- The depth and breadth of the policy commitment to service user involvement, in mental health, means that this should be a main plank of service provision and be embedded in practice. However, the locus of user involvement has traditionally been limited to participating in the development of their individual support packages and being told of changes to overall provision. Their involvement in determining the strategic direction of services has been limited. *No Health Without Mental Health* challenges this with its ambition for service users to assume a leadership role in service provision. This will require Health and Social Care to build on their pre-existing partnership arrangements with service users making sure that their voice is heard.
- The alignment of the theory and practice of service user involvement will require statutory agencies to develop very clear ideas about what this means and tools (e.g. the matrix proposed by Peck et al.) with which to monitor and quality assure this activity. This is, particularly, important with respect to Black and ethnic minority communities as the evidence suggests that their ability to influence change is limited.
- The alignment of the theory and practice of service user involvement will also require a well planned approach to *information* and *communication* being put in place. These activities are regarded as pre-requisites of user involvement at both the macro and micro-commissioning levels. Without good and effective *information* and *communication* service users will be deprived of the ability to meaningful participate in service development and decisions effecting their provision. User involvement and leadership is regarded as contingent on the *information* they receive and the effort made to *communicate* with them well.

⁴⁶⁵ Repper, J. & Perkins, R. (2003). *Social Inclusion and Recovery: A Model for Mental Health Practice*. London: Baillière Tindall

⁴⁶⁶ See Sheldon K and Harding E, op cit.

- This aspect of service user involvement points to a degree of service user leadership in their treatment which, in turn, raises issues of professional trust and confidence in those they support. In short, service user involvement demands that, to realise its benefits, professionals must be person centred in their approach and prepared to allow people to take reasonable risks. These are aspects of practice which should be well established and that are suited to recovery programmes.
- The existence of markers means that health and social care economies have the means to, or starting point from which service user involvement can be taken forward in its qualitative and quantitative dimensions. The challenge is for economies to put in place and then use, on a recurrent basis, markers of involvement.
- There are a number of critical ingredients (e.g. *information* and *communication*) in creating excellence in service user involvement. However, statutory agencies must be committed to making it happen, to actively managing the quality of involvement and to reviewing their traditional partnerships with service users to make sure that they are more equal.

INFORMATION: A REVIEW OF THE LITERATURE

Scope

This paper reports the findings of a review conducted to answer one important question:

1. What does the evidence say are the effective mechanisms to communicate information to service users and carers?

A high level but pragmatic overview of the available evidence on the contribution *information and communication* can make to the wellbeing of people with mental health needs is detailed in this paper. Due to resource and time constraints it was not possible to offer a full systematic appraisal of all available evidence which restricts the degree to which any findings and conclusions can be extrapolated from. However, some useful insights are provided. The material to be examined has varying degrees of applicability to different interest groups. For example, that relating to the structure of *communication plans* is likely to be of more interest to politicians, policy makers and commissioners than clinicians who may find the evidence about the benefits of good *information and communication* for their patients of greater value. Nevertheless, the basic principles of good *communication and information practice*, discussed below, are regarded pertinent to all working with people with mental health needs and their carers.

Introduction

Information concerns “*what is conveyed or represented by a particular arrangement or sequence of things.*”

Communication has been defined as “*the imparting or exchanging of information by speaking, writing, or using some other medium.*”⁴⁶⁷

The definition of mental health service users makes clear the importance of *information and communication* when ensuring that: “*The patient is king*”⁴⁶⁸. More tellingly, following on from *Putting People First* (2007⁴⁶⁹), the cross Government strategy, *No Health Without Mental Health* (2011)⁴⁷⁰ stresses that:

“*No decision about me without me’ is the governing principle. Care should be personalised to reflect people’s needs, not those of the professional or the system. People should have access to the information and support they need to exercise choice of provider and treatment.*” (p.3)

However, while the importance of *information and communication* are acknowledged within the mental health arena these terms are often used synonymously although they are not the same. This is made clear by the above definitions for while *information* is the ‘message’ it does not incorporate the idea of ‘exchange’ between *information* providers and receivers. As G. Ossimitz⁴⁷¹ points out:

⁴⁶⁷ <http://oxforddictionaries.com/>

⁴⁶⁸ Milburn A., cited Rose D (2001), “*Users’ Voices: The Perspectives Of Mental Health Service Users On Community And Hospital Care*”, The Sainsbury Centre for Mental Health

⁴⁶⁹ Local Government Association, ADASS, NHS (2007), “*Putting People First*”, HMSO

⁴⁷⁰ HM Government (2011), “*No Health Without Mental Health: A Cross Governmental Mental Health Outcomes Policy For People Of All Ages*”, HMSO

⁴⁷¹ Ossimitz G. (2002), “*Information, Communication And Social Awareness*”, http://wwwu.uni-klu.ac.at/gossimit/pap/go_icsa.pdf

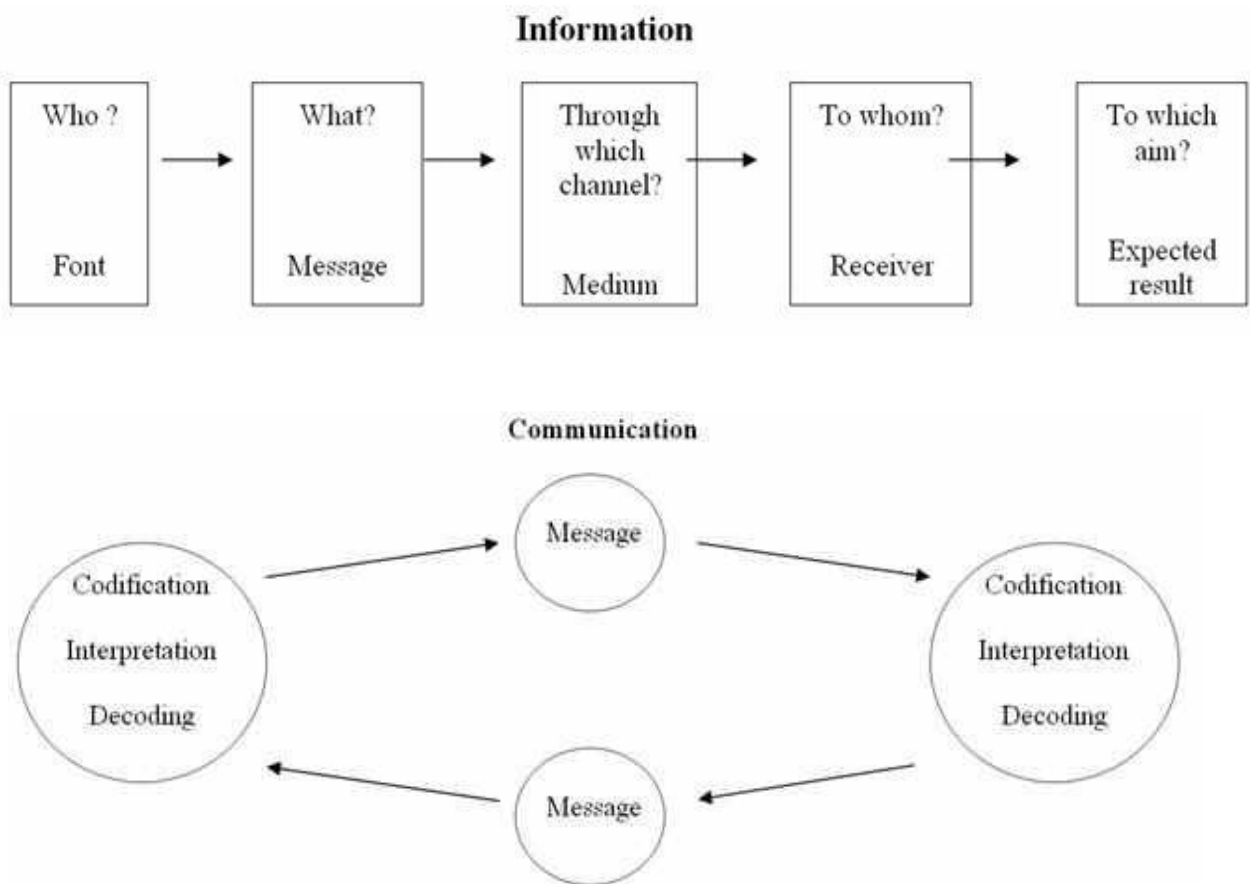
“An essential aspect of information is that it is asymmetric. In classical information theory there is a clear distinction between sender and recipient with information transmitted just in the indicated direction”.

In contrast, the idea of ‘exchange’ sits at the centre of communication:

“...contrary to information, communication needs more than just a one-way stream of information... Communication means to share something and this implies a symmetrical relationship.”⁴⁷²

The following diagram illustrates the difference between *information* and *communication*. It makes the point that *communication* is more than *information*. It (*communication*) is *information in action* or an *exchange of information* which allows views, ideas and feelings to flow and be swapped.

Figure 1. Difference between information and communication



Source: <http://www.eugad.eu/wiki/index.php/File:Communication.jpg>

⁴⁷² ibid

Methods

The methodology employed by this paper hinges on the attempt it makes draw on learning from general *information* and *communication* theory and practice and then linking this with related evidence that is mental health specific. It is an approach that is premised on the assumption that to *inform* and *communicate* well practitioners and their agencies must have shared and rounded understanding of what these complex activities involve.

Therefore, this paper commences by unpacking what is meant by *information* and *communication* before moving on to consider the approach to be taken to developing a communication plan and setting out some generic good practice principles and standards. Subsequently, *information* and *communication* within the mental health arena will be considered along with the benefits of performing both these tasks well. This paper will then be brought to a close by outlining the conclusions that emerge from the literature reviewed and their associated implications.

Defining a 'Mental Health Service User'

Before proceeding it is important to be clear about what is meant by '*mental health service users*' or '*someone with mental health needs*'. This is a possible source of confusion since, according to Tait and Lester (2005),⁴⁷³ the language used to describe these people is more varied than in any other sector of health and social care. Traditionally they have been portrayed as patients - as objects of the clinical gaze⁴⁷⁴ but, more recently, they have also come to be regarded '*consumers*', '*survivors*' and '*providers*' all of which imply different notions of the roles and responsibilities held by people with mental health needs.

Tait and Lester (op cit) point out that while users are increasingly seen as '*consumers*' (i.e. '*customers*') who can exercise '*informed*' choice the force of this empowering concept is diluted by a public focus on, and a political concern with the risks the mentally-ill present to society. As a result risk management and the safety of the general public has impeded the development of consumer rights within mental health.

The notion of the user as a '*survivor*' developed rapidly in the 1980s and 1990s⁴⁷⁵ and offers a positive image of people with mental health needs as individuals who have the strength to survive the mental health system. This conceptualisation of service users has underpinned the development of user-led services:

"The movement...needs to remain independent in order to offer critical comment on services and to provide alternative sources of support and information, while being strong enough to have a real impact on mainstream service delivery for those with severe and long-term problems." (p.1)

The identification of service users as '*providers*' is reflected in the development of user-led services which are found across the statutory and voluntary sectors throughout the country. In Tower Hamlets the Borough Council and its NHS partners jointly commission a range of successful services provided by user led organisations. This has bolstered the strongly and positively correlated definitions of users as '*consumers*' and '*survivors*' which, in turn, supports their definition as '*providers*'.

⁴⁷³ Tait L. and Lester H. (APT 2005, 11 168-175), "*Encouraging User Involvement*", Mental Health Services, Royal College of Psychiatry.

⁴⁷⁴ Pilgrim D. and Rogers A. (1999), "*A Sociology Of Mental Health And Illness*", Buckingham: Oxford University Press.

⁴⁷⁵ See Wallcraft J. With Read J. And Sweeney A. (2003), "*On Our Own Terms: Users And Survivors Of Mental Health Services Working Together For Change*", The Sainsbury Centre for Mental Health

In short what emerges from the debate about the definition of mental health service users is that they cannot simply be described as patients or as any one *'thing'*. They sit at the centre of a, figurative, Venn diagram and can be regarded as *'consumers'* and *'survivors'* and *'providers'* and (sometimes) *'patients'*. The definition is multifaceted and dynamic.

Findings

This section presents, as succinctly as possible, the main themes and finding that emerged from the literature reviewed.

Developing a Communications Plan

In any complex undertaking it is vital to develop a communications plan that will allow the exchange of ideas. Unfortunately, it is difficult to pin down within the literature what the template for such a plan should look like. However, Dave Fleet (2008)⁴⁷⁶ and the *Communications Planning eBook*⁴⁷⁷ are both helpful. The advice of both is synthesized in the rest of this sub-section with a communication plan described as consisting of the following stages:

- ***Setting the Context*** - What's happened before? What's the history?
The purpose of this stage of the plan is to set the scene, to identify the topic, or topics to be focused on and to set-out the timeline.
- ***Environmental Scan*** - What are the key factors that will affect the success of the plan?

The environmental scan looks at external factor which may impact on a communications plan. A PEST (Political, Economic, Social, Technological) analysis is a useful way to begin to think through an environmental scan which is, particularly, apposite to a local government setting in which political drivers will be important considerations.

- ***Stakeholders*** – Who are the stakeholders and what are their expected reactions?
How will they be managed?

The stakeholder analysis should cover everyone affected by the initiative the communications plan is about. Consider the positions of stakeholder groups with respect to an initiative, **how the support of those expected to react positively might be used and the concerns of those expected to react negatively can be mitigated**. A common gap in communications plans is the failure to identify potential negative reactions.

- ***Strategy*** – What is the purpose of a communications plan and how is it going to be achieved?

The strategy should include its profile (i.e. high or low), whether a reactive or proactive approach will be taken by the communications effort and how stakeholders will be reached.

- ***Objectives*** - What is to be achieved? (Be SMART⁴⁷⁸).

⁴⁷⁶ <http://davefleet.com/2008/05/how-to-write-a-good-communications-plan-part-1-an-overview/>

⁴⁷⁷ <http://links.visibli.com/2d4ec98c82e7ca77/?web=b66663&dst=http%3A//www.slideshare.net/davefleet/strategic-communications-planning-a-free-ebook>

⁴⁷⁸ Specific, Measureable, Achievable, Realistic, Time-bound

Objectives should be specific and it is important to be clear about the difference between business and communications objectives. The two should not be confused.

- **Audiences** – Who are the key audiences?

Analyse the key groups or people to be reached and their communication and information needs. Make sure there are not any gaps in the chosen audiences. Gap-filled or imprecise audience selection leads to an unfocused, ineffective roll-out of communications. Conversely, well-defined audiences allow messages and tactics to be crafted appropriately to achieve set objectives.

- **Key Messages** –What are the key messages?

This is all about what messages communicators are trying to relay to people. If the audience is to take something away from a communications exercise what should these messages be? The following should be considered:

- Communicating, in the case of changing, what is changing and why.
- Communicating what will be different.
- Communicating the fit between what is communicated and the communication objectives.
- Communicating messages in ways that speak to all audiences.
- Communicating messages simply, making them in no more than one or two sentences and using plain English.

- **Tactics** – How will the strategy be implemented - before, during and after the main announcement (assuming there is one)?

Tactics should flow from the strategy. The tactics for high and low profile strategies will differ. By putting tactics near the end of the planning process the implications of a particular initiative are considered from every possible angle. That reduces the risk of defaulting to (possibly) inappropriate news releases and/or media events without thinking them through.

- **Issues** – What problems may have to overcome?

Issues management is about catching problems before they become crises. Think through how issues can be mitigated.

- **Budget** – How much will the communication plan cost to implement?

The roll-out of most communications plans will have a cost. A solid case for this expenditure will have to be made and a detailed breakdown of these costs prepared.

- **Evaluation** – How will it be known the communications plan has been successful?

Measurements should be related to the objectives of the communication plan and might include metrics relating to media coverage, stakeholder reaction, public enquiries, benchmarking etc.

Generic Good Practice Standards When Communicating and Informing

Having outlined good practice in developing a communications plan this sub-section goes on to considered some basic features of good practice when actually communicating with and

informing real people. The starting point for this undertaking is provided by Janice Obuchowski⁴⁷⁹.

“Jargon and puffery are bad news... they generate boredom and confusion. And an audience that is bored and confused is an audience that isn't being persuaded. It's easy to fall into the trap of using the important sounding but vague expressions that constitute so much business communication today. But to get your message across and convince others to follow where you want to lead, you need to convey your thoughts in clear, concrete, and compelling language”.

Obuchowski's injunction to use clear and easily understood language that does not mystify audiences is picked up by the Plain English Campaign. It calls for communication, in all forms, to be characterised by:

- The use of short sentences.
- The use of active verbs.
- The use of 'you' and 'we'.
- The use of words that are appropriate to the reader.
- The use of instructions, where appropriate.
- The use of lists where helpful.
- The avoidance of nominalizations.

For the Plain English Campaign⁴⁸⁰ good information and communication practice hinges on thinking about what points need to be conveyed to the audience, using everyday English and words that are appropriate to the audience while being as concise as possible. Public agencies need to consider the degree to which they meet these good practice standards.

The customer care literature emphasises that good communication is also about listening and receiving feedback – communication is a two way process. *Making Experience Count*⁴⁸¹ and *Listening, Responding, Improving: A Guide to Better Customer Care*⁴⁸² both stress the importance of listening to people across the NHS and social care. This means thinking about the ways people find out about and inter-act with their services which must give consistent messages, in a consistent tone, across all organisational communications channels. This should be accompanied by a sustained effort to ensure that those who use services have access to engaging and accessible information and receive feedback with respect to any communications they participated in.

The Scottish Parliamentary Ombudsman (SPO)⁴⁸³ provides a concise summary of the hallmarks of good information and communication practice, albeit with respect to complaints handling. When paraphrased, the SPO stress that information and communication must be:

- *User-focused*: The individual/audience is at the heart of the process.
- *Accessible*: Information must be clearly communicated, sufficient to allow people to arrive at an informed opinion, easily understood and available to all.
- *Simple and timely*: The information and communication processes must have as few steps as necessary and take place within an agreed timeframe.

⁴⁷⁹ Obuchowski J. (1st Feb, 2006), “Communicate To Inform, Not Impress”, p. 3 Harvard Business Publishing Newsletters.

⁴⁸⁰ <http://www.plainenglish.co.uk/files/howto.pdf>

⁴⁸¹ <http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Managingyourorganisation/Legalandcontractual/Complaintspolicy/MakingExperiencesCount/index.htm>. Accessed June 2013.

⁴⁸² http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_095408. Accessed June 2013

⁴⁸³ <http://www.valuingcomplaints.org.uk/wp-content/media/principles.pdf>

- *Thorough, proportionate and consistent*: Information and communications must be robust and produce quality outcomes but be proportionate to the matters at issue and conform to a set of clear quality standards.
- *Objective, impartial and fair*: Complaints management is objective, evidence-based and driven by the facts, not by assumptions.
- *Seek early resolution*: Complaints are resolved at the earliest opportunity. Apologies and remedies are offered, as appropriate.
- *Deliver improvement*: Complaints management is driven by the search for improvement, using analysis of outcomes to drive forward the quality and safety of services.
- *Treating people with courtesy, consideration, openness and honesty*: People are always treated with sensitivity and respect.

Information and Communication in Mental Health

The *Implementation Framework* (2012)⁴⁸⁴ supplementing *No Health Without Mental Health* (op cit) takes the Government's mental health strategy to the next level by translating its ideas into a series of concrete actions which provide an unequivocal policy commitment to improving information for, and communication with people with mental health needs on the part of a wide range of stake holders. For example, the Framework requires:

- *Providers to consider the power of information to transform services*: “Innovative use of information has the power to transform mental health services, and will be essential in implementing the mental health strategy”(ibid,p.19). This reflects the recommendations of Mind's report, *Listening to experience: an independent inquiry into acute and crisis mental healthcare* (2011)⁴⁸⁵. It is also relevant to the duties and obligations set out in the NHS Constitution.
- *Providers to focus on choice, recovery and personalisation*: “This includes considering how service users' perceptions of recovery can be incorporated into all elements of clinical practice and working to ensure people have appropriate support and access to advice and information”⁴⁸⁶. This could include advice on housing, benefits and debt as well as employment based employment support, training and education.
- *Primary medical care will*: “Offer people a range of treatment options, provide information to support treatment choices, and signpost to advocacy support where appropriate”⁴⁸⁷.
- *Local Authorities will*: “Involve the local community, including those with mental health problems, their families and carers, in the co-production of service pathways and in service design. This includes providing clear and accessible communication regarding how people's views and priorities have been taken into account.”⁴⁸⁸
- *Community Groups should*: “Raise awareness of mental health amongst relevant organisations. This could include public services, businesses and other private sector organisations.”⁴⁸⁹

In short the emphasis the *Implementation Framework* places on *information* and *communication* make it clear that they are two primary means of delivering the vision of *No*

⁴⁸⁴ Centre for Mental Health, Department of Health, Mind, NHS Confederation Mental Health Network, Rethink Mental Illness, Turning Point. (2012), “*No Health Without Mental Health: Implementation Framework*”, HMSO

⁴⁸⁵ http://www.mind.org.uk/assets/0001/5921/Listening_to_experience_web.pdf

⁴⁸⁶ *Implementation Framework*, op cit, p.20.

⁴⁸⁷ ibid p 22.

⁴⁸⁸ ibid p.24

⁴⁸⁹ ibid p.30.

Health Without Mental Health. The political imperative to improve *information* and *communication* is unmistakable and is allied to the belief that increasing access health and care information has the power to transform services, including mental health services, at both the level of individual service users and service providers⁴⁹⁰. The professional challenge is to *inform* and *communicate* well.

The DOH information strategy *The Power of Information* (2012)⁴⁹¹ provides explicit recognition of the importance and power of good *information* and *communication*. It sets out a ten-year programme for the complete overhaul of information for the NHS, public health and social care with the objective of putting people in control of their own health and social care information. Accompanying this initiative is the Government's commitment to implement consistent information standards that will be applied across healthcare, public health and social care by 2018.

The Power of Information has profound implications for mental health as is recognised by the *Implementation Framework* which observes that:

"Implementing the vision it (The Power of Information) sets out in mental health services will be essential in meeting the objectives of No Health Without Mental Health" (p.41)

However while current the political and policy context provide strong injunctions to improve *information* for, and *communication* with people who have mental health needs and *'feels'* like the right thing to do, what is the evidence that it produces benefits for service users and their families and their informal carers? This question is turned to in the next sub-section of this paper.

The Benefits of Informing and Communicating Well

*"Communication skills are fundamental to good clinical care and facilitate detection of psychological problems..."*⁴⁹²

*"Accurate information can give people more sense of power"*⁴⁹³

*"Allowing people to have a voice - by listening to their story, by giving them a say in the running of their services..."*⁴⁹⁴

According to Shepherd, Boardman and Slade⁴⁹⁵ the aim of professional intervention dedicated to promoting recovery is to provide the person with the support they need to, as far as possible, manage their own condition and get access to those resources they feel they need to live their own lives. This, explicitly, means providing people with the right information, at the right time, in the right way. Properly given, *information* is a cornerstone of recovery.

⁴⁹⁰ See *ibid* p.41

⁴⁹¹ <http://www.dh.gov.uk/health/2012/05/information-strategy/>

⁴⁹² Royal College of Physicians and Royal College of Psychiatrists (2003)

⁴⁹³ Deegan P (1993) *"Recovering Our Sense Of Value After Being Labelled Mentally Ill"*, *Psychological Nursing and Mental Health Services*, 31 (4) pp. 7-11

⁴⁹⁴ Deegan P. E., *"Recovery The Lived Experience Of Rehabilitation"*, *Psychological Rehabilitation Journal* 11 (4): pp 11-19, 1988

Deegan (1996), *"Recovery As A Journey Of The Heart"*, *Psychiatric Rehabilitation Journal*, 19, pp. 91-97.

All the above references taken from Sage C., *"Holding The Hope"*, Tower Hamlets Rehabilitation and Recovery Team.

⁴⁹⁵ Shepherd G., Boardman J. and Slade M (March 2008), *"Making Recovery A Reality"*, Sainsbury Centre for Mental Health

This message is endorsed and expanded upon by South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust (SLAM/SWLSTG)⁴⁹⁶ which place *information* at the heart of the recovery model. They state:

“Recovery, is designed to provide people with severe mental illness with the information and skills necessary to manage their illness effectively and work towards achieving personal recovery goals. The benefits for service users include an increased their knowledge of illness, coping skills, personal goal identification and attainment”.
(p.15)⁴⁹⁷

However, SLAM/SWLSTG goes on to point out that within the recovery model simple *information* giving is not enough. It is vital to listen to what the person wants in terms of therapeutic interventions, e.g. psychological treatments, alternative therapies, joint crisis planning etc. It is important for the person to know that they have been listened to, that their views are being treated with respect and that professionals want to work with them in partnership. It is at this point that the process of *information* giving (the message) tips over to become the interactive process of *communication* which when done well is associated with:

- Improved outcomes for people.
- Reduced anxiety and increased satisfaction on the part of service users.
- Adherence to medical advice.
- Improved knowledge and understanding on the part of users⁴⁹⁸.

However the Royal Colleges of Physicians and of Psychiatrists, as does the Plain English Campaign, recognises that a common *communication* problem is the use of jargon and technical terms. In short poor *communication* cannot be regarded as true *communication*. It may be no more than an exercise in disempowerment and obscurity. The professional challenge is, one again, to *communicate* WELL and the essentials of good *communication* in a clinical setting are:⁴⁹⁹

- Expressing an interest in the person (i.e. the service user).
- Eliciting the person's beliefs and concerns.
 - Acknowledging and responding to the person's distress.
 - Avoiding the use of jargon and overly complex information.
 - A collaborative and empowering approach.
 - A willingness to listen in a person centred way which allows advice and *information* to be given within the person's own framework and understanding and promotes agreement about the best course of action.
 - An awareness of any language, cultural or religious factors which may impede communication if not properly understood and responded to.
 - Privacy and confidentiality, as appropriate.

Effective *communication*, in addition to the benefits outlined above, unlocks the participation of people in their own treatment plans. They become decision makers and Shepherd et al, SLAM/SWLSTG, Mueser *et al.*, the Royal College of Physicians and the Royal College of Psychiatrists all associate this with reduced anxiety and depression i.e. improved

⁴⁹⁶ South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust (2010), *“Recovery is for All. Hope, Agency and Opportunity in Psychiatry. A Position Statement by Consultant Psychiatrists”*. London: SLAM/SWLSTG.

⁴⁹⁷ Also see Mueser, K.T., Corrigan, P.W., Hilton, D.W. Tanzman, B., Schaub, A., Gingerich, S., Essock, S.M., Tarrier, N., Morey, B., Vogel-Scibilia, S. & Herz, M.I. (2002), *“Illness, Management and Recovery: A Review of the Research”*, *Psychiatric Services*, 53, 1272-1284.

⁴⁹⁸ Royal College of Physicians and Royal College of Psychiatrists (2003), *op cit* p. 7.

⁴⁹⁹ *ibid* pp.8-9.

psychological outcomes, both emotional and behavioural. Facilitating the role of the service user as a decision maker involves moving from the provision of the *information* needed form judgements about decisions taken to entering into a *communication* in which decisions can be shared, weighed and made.

While the evidence clearly demonstrates the importance of good *communication* and *information* to people with mental health needs there is a substantial body of work which also indicates their importance to families and informal carers. This is summarised by Burrough⁵⁰⁰ who stresses that most carers require some form of support and advice. *Mental health literacy* has been described as “*knowledge and beliefs about mental disorders which aid their recognition, management and prevention*”⁵⁰¹ and it is recommended as a key target of intervention with carers and families.

The importance of promoting *mental health literacy* for children living in families in which adults have mental health needs is highlighted by Burrough who observes:

“Research with young carers suggests that many hold misconceptions about their parents’ illness which may result from unnecessary worries about or distress. It is thus suggested that young people also need information about parental mental illness. Children themselves have reported a desire to have information about their parents’ mental illness and have identified that an understanding of mental illness is critical in relieving self-blame for parents’ behaviours arising from mental illness and developing an independence from their parents’ illness”. (p.16)

The importance of good *information* and *communication* in sustaining caring relations, in helping to ensure that carers continue to care is recognised by NICE⁵⁰². More specifically, with respect to schizophrenia, it recommends that carers should be given information about this condition and its management and describes the discussions that should take place with carers to help them cope as those they care for go through their treatment programmes.

The *information* carers require has been identified as falling into two broad categories. First there is specific information regarding the person they care for including their illness, the medication or treatment prescribed and its possible effects.

Second, carers require less specific *information* about the range of different issues including the effectiveness of various treatments available, the impact of legislation, welfare rights and local support services for carers.

The Royal College of Psychiatrists has produced a checklist⁵⁰³ which aims to support psychiatrists in giving carers the *information* they need which focuses on diagnosis, treatment and support for the person cared for. Another checklist⁵⁰⁴ is designed for carers themselves with guidance regarding the kinds of questions to ask and *information* to gather to both empower the carer and improve the carer-practitioner relationship.

However, after her survey of the literature Burrough concludes that:

⁵⁰⁰ Burrough M-C, Briefing paper: “*Support For Carers Of People With Mental Illness*”, Whole Systems Mental Health Review, Chapter 2.3, Tower Hamlets

⁵⁰¹ Jorm AF, Korten AE, Jacomb PA, Christensen H, Rodgers B, and Politt p (1997), “*Mental Health Literacy: A Survey Of The Public’s Ability To Recognise Mental Disorder And Their Beliefs About The Effectiveness Of Treatment*”, Medical Journal of Australia, 166, pp 182-186

⁵⁰² National I f H and CE (2009), “*Clinical Guideline Schizophrenia: Core Interventions In The Treatment And Management Of Schizophrenia In Primary And Secondary Care (Update)*”, NICE: London.

⁵⁰³ <http://www.rcpsych.ac.uk/pdf/psychiatrists.pdf>

⁵⁰⁴ <http://www.rcpsych.ac.uk/PDF/carers.pdf>

“Evidence is supportive of carers need for better and timely access to information which could include information regarding the condition of the person they care for, on what constitutes ‘appropriate caring’, on accessing benefits and other sources of support, on mental health services available etc.... Education as information is an important supplement to other interventions....” (p.20)

What emerges from the literature is that while *information* and *communication* are inadequate as a sole response to the public’s understanding of mental illness, to the experiences of carers and to the needs of service users they are critical to making progress in all three areas. However, to be effective *information* and *communication* must be activities must be done well. Reference has been made herein to different approaches to *informing* and *communicating*, which need, to be adjusted to the needs of the audience and the purpose of the *information* and *communication* but need to be planned, clear, timely, person centred are consistent requirements. Finally, it needs to be remembered that *informing* and *communicating* well includes *listening* actively to what service users have to say.

Conclusions/Recommendations

- *The Definition of Mental Health Service Users:* The definition of *mental health service users* is dynamic and multifaceted with them being regarded as, for example, ‘consumers’ and ‘survivors’ and ‘providers’ and (sometimes) ‘patients’ at different or the same times. As a result, the definition has become elusive and imprecise.
- *The Difference Between Information and Communication:* *Information* and *communication* are not the same. *Information* is a one-way process which is about ‘telling’ while *communicating* is two way activity that involves ‘telling’ and ‘listening’.
- *Communications Planning:* *Communication plans* are important but complex. They are the means by which politicians, policy makers and commissioners can proactively manage dialogue with the public and/or specific stakeholder groups. This is, particularly, important if changes to provision are being proposed which some may find difficult. However expertise in *communications* tends to be limited to a few communications and customer care professional
- *Good Practice: Keep It Simple:* A central message to emerge from the examination of good *information* and *communication* practice is keep it simple. The injunction is to avoid jargon and to use everyday English (or any other appropriate language).
- *Good Practice: The Hallmarks of Good Practice:* There are hallmarks of good communication practice – see above – which social and health care organisation should consider adopting or adopting variations of. This will allow their *information* and *communications* to be quality assured.
- *The Benefits of Informing and Communicating Well:* There is considerable evidence that ‘*informing*’ and ‘*communicating*’ WELL with people who have mental health needs is more than a political good. Research indicates that when services users are effectively *informed* and *communicated* with their outcomes are improved, they are empowered, their recovery is promoted, anxiety levels fall as satisfaction increases while there is increased adherence to medical advice. However, failure to *inform* or *communicate* or to do so badly has the reverse effect. It disempowers, raises anxiety, reduces outcomes, undermines recovery and adherence to medical advice.

- *The Policy Context:* There is an evident and significant national and policy political imperative with *No Health Without Mental Health*⁵⁰⁵ stating that professionals must work with individuals to help them identify and achieve the outcomes that matter to them. A task that places a premium of good *information* and *communication*.
- *User Involvement:* *Information* and *communication* are regarded as pre-requisites of user involvement at the strategic and micro-commissioning levels. Without good and effective *information* and *communication* people are deprived of the ability to meaningful participate in developing services and taking decisions effecting their provision.
- *Carers:* The research evidence warns against treating mental health service users as though they live in a vacuum. Their social relationships must be taken into account, particularly, those of their family members and informal carers. The ability of many people with mental health needs to remain independent within the community is dependent on the maintenance of these caring relationships which can be placed under unnecessary, but critical pressure by the failure to *inform* and *communicate* with them effectively. Efforts in this respect should be geared toward increasing the *mental health literacy* of carers.

Implications

- Failure to develop a definition of people who use mental health services may mask a misunderstanding of their support needs as individuals and as a group and lead to inaccurate labels being applied for the convenience of the labeller. This risks the development of approaches to *information* for and *communication* with people with mental health needs which are inappropriate.
- *Information* and *communication* have fundamentally different meanings but are often used synonymously. This risks obvious confusion with so-called attempts of *communication* taking the shape of *information* giving and vice versa. It is a, particular, risk in the public sector where the traditional 'gift' relationship between those who provide and receive services is only now beginning to be replaced by personalisation.
- Moreover, failure to use the words *information* and *communication* properly erects a barrier to the attempts made by statutory agencies to carry out both of these activities well.
- *Communication planning* should be a core feature of change programmes including the development and implementation of mental health strategies. The template provided in this paper offers a starting point for this work and may be modified as appropriate. Lack of effective *communication planning* may make organisations appear furtive, raises anxiety among service users and their carers, creates avoidably bad press, leads to political and reputation risks and can undermine the relationship (i.e. partnership) between service users and professionals.
- This conclusion provides a reminder to local government and NHS officials not to fall into the trap of using acronyms and puffed-up, abstruse language. The use of such language is habit forming and needs to be replaced by the habit of using plain English which organisations that want to be good at *informing* and *communicating* need to promote.
- Organisations wishing to quality assure their *information* and *communications* will need to invest in a monitoring function to audit these activities. The affordability of making this investment may be an issue. However, within mental health *information* and *communication* are not optional. Current policy makes clear that service users must be effectively involved in the development of their individual support packages and in

⁵⁰⁵ Op cit, p.16

deciding the strategic direction of services. This means, by implication, that professionals must learn how to *inform* and *communicate* well and to do so consistently.

- *Information* and *communication* emerge from the literature as important tools in supporting people with mental health. Done WELL these activities can lead to enormous benefits, and increase the cost-effectiveness of provision but the risks of their poor performance should not be overlooked. This is a key professional challenge for practitioners and their managers who must *inform* and *communicate* in person centred ways while adopting quality markers to actively understand how well they are conducting these important activities and manage them accordingly.
- While *No Health Without Mental Health* has given a renewed and added impetus to the need to *inform* and *communicate* well. This requirement is not new⁵⁰⁶ and should already be embedded in practice. The managerial challenge is to think through how organisations will know just how well they are actually *informing* and *communicating* as opposed to how well they think they are doing.
- The main implication of research discussed with respect to this conclusion is that *informing* and *communicating* WELL is a critically important enabler of meaningful user involvement in service provision and planning. The logical corollary of this that if organisations are serious about user involvement they must also be serious about *informing* and *communicating* and take all necessary actions to ensure that this is the case.
- For every person experiencing mental ill-health there will, in most cases, be a family (the carers) effected by and living with that illness. Therefore, it is important that families, not just service users, are properly supported. In this regard one of the most important things that can be done to help families and carers to continue to care is to provide them with the *information* they need and to *communicate*.

⁵⁰⁶ For example see NHS and Community Care Act (1989), DOH, *Patient's Charter* (1991), NHS Management Executive, *Local Voices* (1992), DoH, *Modernising the NHS* (1997), DoH, *NHS Plan* (2000), *Health and Social Care Act 2001*, DoH, *The Health of the Nation* 1992), DoH, *Working in Partnership* (1994), DoH *Building Bridges* (1995), DoH, *Our Health, Our Care, Our Say* (2006), DoH, *High Quality Care for All* (2008), HMSO, *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care* (2007), DoH, *A Vision for Adult Social Care: Capable Communities and Active Citizens* (2010) and HMSO, *Health and Social Care Act 2012*