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Title: The role of youth mental health services in the treatment of young people with serious mental illness: two-year outcomes and economic implications

Short running title: Youth mental health services

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Correspondence to: Nicola Brimblecombe, Personal Social Services Research Unit, London School of Economics & Political Science, Houghton Street, London, WC2A 2AE, UK. <u>N.s.brimblecombe@lse.ac.uk</u>. Telephone: 44 (0) 207 955 6376. Fax: 44 (0) 207 955 6131 THE ROLE OF YOUTH MENTAL HEALTH SERVICES IN THE TREATMENT OF YOUNG PEOPLE WITH SERIOUS MENTAL ILLNESS: TWO-YEAR OUTCOMES AND ECONOMIC IMPLICATIONS

ABSTRACT

Aim: To evaluate the outcomes and economic case for a UK innovative youthspecific mental health service for 16 to 25 year olds.

Methods: A pre-, during- and post-treatment comparative design for twenty young people at high risk of developing psychosis who received two years' treatment with the service, using outcomes that concurred with the service aims: changes in mental health, employment rates and service use.

Results: 45% of those at risk and with symptoms of serious mental illness commencing treatment were not receiving mental health services at baseline.. Compared to service use prior to treatment at the youth-specific service, hospital admissions, A&E and criminal justice system use appear to decrease over the two years of treatment and the year after treatment, with potential cost differences of £473,000. Mental health improved or stayed the same, compared to baseline. Employment rates improved, although the sample size for this is very small. Potential cost differences associated with service users moving into employment over the two years are £148,000. The estimated cost over two years of providing the youth-specific mental health service to these young people was £106,000.

Conclusions: Given the extensive long-term negative consequences and high costs of untreated mental illness in the 16 to 25 age group and the documented problems young people have in receiving appropriate services, this youth-specific, age-appropriate service model appears to be successful, with improved outcomes and

cost differences in the short-term, and with encouraging implications for the longer term.

Key words: Adolescent Health Services, Costs, Evaluation, Mental Health Services, Young Adult

THE ROLE OF YOUTH MENTAL HEALTH SERVICES IN THE TREATMENT OF YOUNG PEOPLE WITH SERIOUS MENTAL ILLNESS: TWO-YEAR OUTCOMES AND ECONOMIC IMPLICATIONS

INTRODUCTION

Mental health problems account for a significant proportion of the burden of ill-health for young people in the UK (1) and internationally (2). Prevalence of mental illness increases during adolescence and problems become more complex (3), with long-term morbidity and mortality among the highest of any age group (4). Recent societal changes such as the increase in youth unemployment and increasing instability of employment, poverty and insecure housing, all of which are among the known risk-factors for mental health problems in this age group (5-7) may mean that young people are at increasing risk.

The majority of mental illnesses start during adolescence and persist into adulthood (8, 9). They are associated with poor short- and long-term health, negative social, educational and economic outcomes for the young people themselves and for their family and carers, with financial costs to health and other services such as the criminal justice system (CJS) (8-14). Mental illness is associated with behaviours likely to result in poorer physical health in adulthood, such as alcohol misuse, smoking, and substance use (15, 16).

The peak onset of problems in this age group and the long-term consequences if untreated means there is both a need and a prima facie case for early intervention and prevention for young people (17). Despite this, current services do not serve this population well. Underdiagnosis or misdiagnosis (18), a reluctance to access services (19), negative attitudes about seeking professional help (20), discomfort with receiving a formal diagnosis

(21) and feeling that current services are inappropriate for their needs (19, 20, 22) have resulted in a mismatch between needs and service provision. The result is that many young people do not receive any clinical intervention. In 2004, only 25% of children in Great Britain with mental illness were in treatment (18) and this had not improved by 2010 (23). Of the minority who do access treatment, many drop out or do not engage (24-26) and there is an increase in disengagement from childhood to adolescence (27). Certain sub-groups are further underrepresented. For example, people from Black and Minority Ethnic (BME) backgrounds are less likely to access mental health services (28, 29). The recent cuts in the UK - not only to mental health services but also in social care and education - may disproportionately affect those who are already socially disadvantaged (30). Two recent reports by the Chief Medical Officer for England (1, 31) recognise deficiencies in the way that current services respond to the mental health needs of young people, particularly the most vulnerable.

Transition from child and adolescent mental health services to adult services may present a particular problem (32). At a time when young people are undergoing many other key transitions in their lives, they often 'fall through the gap' during this service transition. *Closing the Gap,* the UK government's mental health policy statement for England (33), acknowledged both this problem and the consequences: it concluded that 'this "cliff-edge" situation must end.'

One possible solution to improving access, engagement and acceptability is ageappropriate, youth-specific mental health services (34) and UK Government policy has recognised needs in this area (35-37). Viner (38) found that age-appropriate inpatient services for 12 to 17 year olds in England improved attendance, retention and quality of care. However, according to Bailey (4) 'in dramatic contrast to the numbers of adolescents using services and their perceived special needs... there is a relative dearth of specific or discrete services for young people within all our health services' (p18). Although youth-specific models have been developed to an extent in other services, this has not been the case in psychiatric care (4), although a few have recently emerged in the UK. There are few data, particularly economic data, on services and outcomes for youth mental health services in the UK (10, 39), which may be in part because of the rarity of this type of service model. Of the available published evaluations of youth mental health services in the UK, an evaluation of the Youthspace service for 16 to 25 year olds in Birmingham (40) found higher levels of engagement, attendance and acceptability. Results for youth advice services for 14 to 25 year olds (41) showed an improvement in mental health and related stressors, in particular housing, with associated cost savings. In Australia, the evaluation of the headspace programme (42) found that it has been effective in promoting and facilitating improvements in some young people's mental and physical health, alcohol and drug use, and their social and economic participation.

Our study aims to evaluate the outcomes and economic costs for Tower Hamlets Early Detection Service (THEDS), an innovative youth-specific mental health service.

METHODS

Intervention

THEDS was set up in 2009 to provide mental health education, support and services to young people aged 16 to 25 in Tower Hamlets, London, who may be at risk of psychotic illness. The main focus is preventing or delaying the onset of psychosis; however they also offer services to other young people who are in distress.

All young people who are referred or self-referred are offered a three-month brief intervention incorporating medical review by a psychiatrist, psychological assessments, information about how to keep mentally well, signposting to other services, and access to work and training opportunities. In the first 32 months of operation 147 assessments were carried out. Of those, 28% (n=41) were assessed as being at ultra-high risk (UHR) of developing psychosis, using the Structured Interview of Prodromal Symptoms (SIPS) and the Scale of Prodromal Symptoms (SOPS) measures, and were provided access to the service's two-year intervention. This includes an allocated caseworker, access to psychological therapies, family intervention, biopsychosocial interventions and work and training support. Pre-, during- and post-treatment data were available for 20 of those young people and this comprises our sample.

Tower Hamlets Borough has a high proportion – 55% compared to 14% nationally – of people from BME backgrounds (43), and in 2010 was the seventh most deprived local authority district in England out of 3,248 (44). Between 2009/10 and 2011/12 Tower Hamlets had the seventh highest, out of 32, standardised hospital admission rate for mental illness in London (45).

.Analysis

We utilised a pre-, during and post-treatment comparative design with each young person acting as their own control, a method used by Green et al (46). It was not possible to find a parallel (comparison) group because of differences in time of collection or characteristics of participants in available datasets, and because of practical and ethical issues in obtaining data about young people who do not use mental health services. We analysed data already

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routinely collected by THEDS from 2010 to 2013. Ethical approval was obtained from the Caldicott Guardian of the NHS Trust in which THEDS is located. Data were anonymised.

We used outcomes that concurred with THEDS' aims in regard to the young people at high risk: improved mental health and prevention from increased severity, and improved employment. We also looked at differences in service use.

For mental health we compared Global Assessment of Functioning (GAF) severity category (47) at baseline to end of treatment. For service use, we compared number of Accident and Emergency (A&E) visits and hospital admissions in the three months pre-baseline to use during the two-year treatment and in the year after discharge. We compared CJS contact in the three months pre-baseline to contact during the two-year treatment period: data were not available for the year after discharge. To calculate service costs we applied relevant national unit costs to the difference in hospital admissions (48), use of A&E (49) and CJS (50). The data available for pre-baseline were for a three-month period. For comparison purposes this was multiplied by four to give an annual use (51). For hospital admissions, we multiplied the unit cost by the average stay for adults in Tower Hamlets, which was 36 days in 2013 (45). This length of stay is for all ages and it may be higher for young people: for under 18-year olds in 2007 length of inpatient stay was 116 days in one UK study (46). For the CJS unit cost a mean cost has been used for all offences excluding homicide.

For each young person we looked at their employment status (employed/not employed) at baseline and over the two years of treatment. The cost of employment gained was estimated using the human capital approach, which has been widely used in other economic evaluations of mental health interventions research (e.g. 52). We used the national minimum wage and assumed an average full-time working week of 35 hours and that there are 48 working weeks in one year. We use a definition of part-time as half-time. Additionally we looked at potential tax revenues and reduced unemployment-related state benefits for employment gained. For benefits, we used a mean of Job Seekers allowance (JSA) and Income Support (IS) because we did not know which of the two the young people were receiving. It is possible to get JSA or IS if working part-time and on a low income so we did not assume that the part-time workers were no longer on those benefits when calculating costs. Costs were discounted for year two and year three using the UK government HM Treasury discount rate of 3.5% (53).

The annual cost of providing THEDS was derived from estimates provided by THEDS for a snapshot caseload of 100 young people at UHR of psychosis using the two-year treatment programme.

RESULTS

Participants

The sample size is 20 young people. The mean age was 21 years, range 18 to 27. Of these, 59% were male, and 82% were from a BME background, mainly Bangladeshi or British Bangladeshi. All had mental health symptoms at baseline as measured by having a GAF score of less than or equal to 70, were considered at UHR of developing psychosis, according to the SIPS/SOPS criteria, did not transition to psychosis, and completed two years of treatment. The most common ICD mental health diagnosis reported is major depressive disorder; others include anxiety disorder, substance use disorder and specific personality disorder. 60% were unemployed at baseline, 45% had a history of self-harm, 40% used alcohol and/or cannabis and 45% had experienced domestic abuse either as a child, an adult or both.

Unmet need

Just under half (45%) of those commencing two-year treatment at THEDS – all of whom were judged to be at UHR of developing psychosis and who were showing symptoms of mental illness - were not receiving mental health services during the previous three months.

Mental health

As can be seen from table 1, 75% of those with mental health symptoms at baseline showed an improvement in mental health at the end of two years' treatment, 25% stayed within the same severity category and none showed worse mental health.

<TABLE 1>

Employment

At baseline 60% (n=12) were unemployed. Five of those were employed by year 1 and a further two moved from unemployment to employment by year 2. Two were enabled to remain in employment from baseline to year 1, and five from year 1 to year 2 (table 2).

<TABLE 2>

Service use

Service use - hospital admissions, A&E, and CJS - was lower after one year's treatment compared to baseline. After two years of treatment, service use remained lower and for some services was further reduced (table 3). For the year after treatment ended, A&E uses and hospital admissions were zero. We do not have post-treatment information on use of CJS.

<TABLE 3>

Costs

Reduction in service use is associated with total cost differences of £473,120. Of this, 70% (£332,095) is associated with reduction in use of NHS services: A&E and hospital inpatient services (table 4). Improved employment compared to baseline is associated with total cost differences of £148,305; however this is based on a very small sample size. This compares to a cost of £106,174 over the period for providing THEDS services for these 20 young people.

<TABLE 4>

DISCUSSION

These results suggest that, consistent with previous research (18, 23), there is a great deal of unmet need for services among young people with mental health needs, with 45% of those assessed as being at UHR of developing psychosis, and already with symptoms, not receiving any mental health services in the three months before baseline (although there is a possibility that they were receiving mental health services at some point prior to this). It also shows the success of this service model in identifying and recruiting young people in need.

THEDS aims to intervene early to improve or prevent the increasing severity of mental illness and 75% of those receiving THEDS services showed improvements in mental health by end of treatment, while none worsened. This can be set in the context of the literature on the persistence of mental illness which suggests that between 50% and 75% of mental illness at this age persists or recurs in adulthood (8, 9, 54-57). THEDS has achieved its aim of improving mental health and preventing its increasing severity for a high-risk group and this is particularly positive because of the difficulties this age group have in accessing and engaging with services. Furthermore, THEDS has a high number of service users from BME backgrounds who may have additional difficulties with accessing services (28, 29).

Unemployment is a risk-factor for mental illness (6, 7) and THEDS also aims to support young people to remain in, or enter, employment. The high baseline unemployment rate in the THEDS sample (60%, compared to 31% of those young people referred to Youthspace (40) and 20% for the population in this age group overall (58)) emphasises the high need of the THEDS users, linked partly to the economically deprived nature of this area of London. Employment improved over treatment time, although the sample size is small.

Use of A&E, hospital admissions and CJS all decreased over the time of treatment and were zero by the end of treatment. One year after THEDS treatment ended, use of all NHS secondary services including A&E and hospital admissions remained at zero and none of the 20 individuals had returned to either THEDS or other mental health services within a year of leaving THEDS. It could be that participants lacked access to mental health services but as they are able to re-refer to THEDS if they need to do so, this seems an unlikely explanation. Emergency and hospital inpatient service use by young people with untreated mental ill health is high (13, 14) and it can be postulated that without treatment at THEDS it would have remained high. Research by Byford et al (59) has shown that an improvement in GAF score reduces mental health service costs and this also seems to be the case here.

Overall potential cost reductions for the 20 young people who completed treatment amounted to £621,425 over the two years' treatment, and, where we have data, for the year after, with approximately half relating to reduction in NHS service use: A&E and hospital admissions. This compares to the cost of providing THEDS for these young people of £106,174. Long-term costs are not given here because it is not known how long the improved mental health and other changes might be sustained. The finding that one year after treatment had ended, and in the absence of any more treatment, the young people had not returned to secondary services is nevertheless encouraging, and the literature on the long-term outcomes and costs of untreated mental illness (10, 12-14, 60-62) suggests that longer-term savings might be achieved.

Strengths and limitations

Data availability for this type of service and age group is extremely limited, resulting in a number of limitations. Our sample size is small (20 young people, with a smaller sub-sample for employment) and based on data availability which raises questions about both sample bias and the extent to which our results can be generalised. Furthermore, we only had data for three-month service use prior to entering THEDS; for comparison purposes we multiplied this by four to give annual use. Although this is a method used elsewhere, it assumes that service use was constant over that time, which may not be the case; we have no way of knowing if this produces an over- or underestimate. Conversely, a strength is the richness of the data. As youth-specific mental health services are still an emerging area, particularly in the UK, there are few sources of data, especially for before and after treatment. We have a range of outcome or impact data, taken at different time points.

We have taken a before-and-after approach for practical reasons and it would have been preferable additionally to have had a parallel comparison group. However, this proved impossible in this case: data for those not accessing THEDS or similar youth-specific services are hard to obtain and much other research in this area, including service evaluations, has not differentiated this age group specifically. We have drawn on the literature to consider what the outcomes might have been without THEDS treatment, but emphasise that further investigation is needed.

Conclusion

Results from the THEDS youth-specific mental health service show improvements in mental health and employment and reduced service use for young people aged 16 to 25 who received two years' treatment, with associated cost differences in the short-term and

encouraging implications for the longer-term. This is a group in high need: at ultra-high risk of developing psychosis, many not previously accessing mental health services, living in an economically deprived area, having personally high levels of unemployment and with histories or abuse, self-harm and substance use. The documented problems that many young people have in receiving appropriate services means that, bearing in mind the study limitations, THEDS is a service model that appears to be successful. The role of ageappropriate services in mental health to address both the extent and long-term consequences of mental illness in young people and the treatment gap should certainly be explored further.

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