A 2014 Progress Report by the Mental Illness and Employment Task and Finish Group

Addressing the serious health inequality of employment outcomes

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FOREWORD

By Rt Hon Norman Lamb MP
Minister of State for Care and Support

Only 5.7% of adults in England in contact with secondary mental health services are in paid employment\(^1\). This is an unacceptably low figure, and one we should be doing everything in our power to address.

We know that people with mental health conditions want to work, yet often they are not receiving support to help them find a job. This is in spite of strong evidence that employment can be considered to be one of the most important factors in promoting recovery and social inclusion.

The Mental Illness and Employment Task & Finish group, which has been passionately led by Marjorie Wallace CBE, Chief Executive of SANE and my colleague Paul Burstow MP, has proved an invaluable and vocal presence in championing this issue throughout 2014.

In no small part, it is a result of this group’s effort which has enabled new policy developments in 2014 including the development of a CCG Outcome Indicator, a Commissioning for Quality Innovation (CQUIN) and a Quality Statement.

Now that the key policy levers are in place, the challenge becomes one of implementation and I was encouraged to see the group’s plans already developed to this effect. I look forward to seeing those plans come to fruition and will continue to lend all the support I can to the group throughout 2015.

Rt Hon Norman Lamb MP
Minister of State for Care and Support
It is well documented that employment is generally good for people’s mental health and that people with severe mental illness, such as schizophrenia, frequently say obtaining work is an important part of their recovery.

However, employment rates for people with schizophrenia are estimated to be at only 6%\textsuperscript{1}, compared with a national employment rate of around 71%. This is despite a number of key policy documents\textsuperscript{2} aiming to address this issue.

SANE, in partnership with Janssen, established the Mental Illness and Employment Task and Finish Group (T&F Group), which we co-chair, in October 2013. The T&F Group incorporates parliamentarians, policy makers and mental health experts. The aim of the group is to raise the issue of mental illness and employment on the political and policy-making agenda and drive forward progress on the following three key policy levers:

1. Supporting the introduction of an indicator within the Clinical Commissioning Group Outcome Indicator Set (CCG OIS) on employment rates of people with serious mental illness
2. Developing a CQUIN target for NHS providers around supporting adults in contact with secondary mental health services to gain and retain employment
3. Encouraging the inclusion of employment support as a key quality area within the NICE Quality Standard on Schizophrenia currently in development

Significantly, NHS England this year announced the introduction of a CCG OIS indicator on “the proportion of adults in contact with secondary mental health services in paid employment”. A draft CQUIN target has also been produced on “Supporting adults in contact with secondary mental health services to gain and retain employment”. Finally in September 2014, the draft quality standard was published by NICE which included the following quality statement, “Adults with psychosis or schizophrenia who wish to find or return to work are offered supported employment programmes”.

This report presents an opportunity to celebrate the progress made in this area. But more importantly, to look forward to how the T&F Group can continue to provide support and challenge on this important issue, and ensure that the new policy lever is used to tackle the discrimination people with severe mental health problems face and close the employment gap.
MENTAL HEALTH AND EMPLOYMENT: WHAT’S THE PROBLEM?

Severe mental illnesses such as schizophrenia are medical conditions that affect men and women equally, and are most likely to be diagnosed between the ages of 15 and 35. This can prove especially debilitating for people at important stages of their personal and professional lives. Symptoms of these illnesses and side effects of treatment can limit a person’s access to educational and employment opportunities, thereby impacting upon their ability to find work and remain employed.

Research suggests that serious mental illness can cause a 64% decrease in the probability of a person being employed as compared to the general population. Indeed, employment rates for people with severe mental illnesses are staggeringly low. The most recent data published by the Health and Social Care Information Centre (HSCIC) shows that 5.7% of adults in contact with secondary mental health services are in paid employment. The national employment rate is around 71%.

National Institute for Health and Care Excellence (NICE) guidance on schizophrenia states that supported employment should be provided for those people with the condition who wish to return to work or gain employment. NICE guidance on bipolar disorder states that supported employment should be available for people who want help returning to work or getting a job. Cochrane systematic reviews show that there are two main types of vocational rehabilitation for people with severe mental illness: Pre-vocational Training and Supported Employment (Individual Placement and Support (IPS) approach).

Recent surveys highlighted that only 21% of people with schizophrenia in the UK were actively looking for work and less than half of these said that they were receiving support to help them find a job – a finding supported by SANE’s report into schizophrenia and employment. The Care Quality Commission (CQC) community mental health survey 2014 showed that a third (34%) of respondents on Care Programme Approach (CPA), and over half of respondents not on CPA (51%), said they did not receive support from someone in the NHS mental health services in getting help with finding or keeping work, but would have liked it.

In addition, recent research shows that young people who have experienced a first episode of psychosis rate highly the importance of work in their lives but feel much less optimistic in terms of the likelihood of gaining employment.

Unemployment amongst those with a severe mental illness presents a significant financial cost. It is estimated that the English economy loses £3.4 billion per year as a result.
WHY EMPLOYMENT MATTERS

For most people, work is a normal part of everyday life. But it’s more than that – a job is the central hub from which many of our other areas of functioning emanate. For people living with severe mental illness, employment can be considered to be one of the most important factors in promoting recovery and social inclusion. It not only provides financial independence but also structure and purpose, opportunities for socialising and developing new relationships, a sense of identity, self-worth and meaning in life. Work enables people who have experienced mental health conditions to take on a stigma-free social role that in most societies is associated with positive identity, status as an employed person, and a contributing member of society. Repeatedly, people with mental health conditions identify obtaining employment as their most frequently nominated goal and see the ability to return to work as a yardstick of their recovery.

Being employed can be an important step on a person’s recovery journey, improving self-esteem and confidence and reducing psychological distress. Those in paid employment are over five times more likely to achieve functional remission than those who are unemployed or in unpaid employment. Conversely, unemployment increases the risk of developing mental health conditions, and is associated with increased rates of mental illness and suicide, as well as higher use of health services and hospital admissions. Meaningful employment is therefore important for maintaining good mental health and promoting recovery from mental health conditions.

Yvonne is a lesbian single mother from London. She was 31 years old when she was diagnosed with paranoid schizophrenia. Yvonne was unemployed and receiving incapacity benefits for over 13 years. In April 2007, Yvonne secured a full-time, paid position working as a support worker for a homelessness charity based in central London and has remained in employment ever since. During this time, Yvonne has relapsed on a few occasions and has spent a short period in prison. Yvonne credits her mental health care co-ordinator and community mental health team for helping her to stay in employment.

“My mental healthcare co-ordinator helped me with my application form and mock interviews. She also provided me with a reference for my application form. Throughout my 7 years of employment, my Community Mental Health Team have been in regular contact with my employer and when I relapsed earlier on in 2014, they were very involved in working with my employer in helping me get back to work again.”

Yvonne Stewart-Williams, Service user
THE STORY SO FAR

In January 2013, SANE surveyed 79 individuals with schizophrenia to understand the major issues relating to finding and staying in work, asking questions about the healthcare barriers and required support. A report of the survey was published which called for the NHS to prioritise employment for people living with severe and enduring mental illness.

In June 2013, SANE and Janssen supported a Westminster roundtable event on employment and schizophrenia, hosted by the Rt Hon Paul Burstow MP. The meeting sought to explore how best to improve employment outcomes for people with schizophrenia. A clear consensus from the session was that a Task and Finish Group (T&F Group) should be set up to look in detail at the policy levers around improving access to employment for people with schizophrenia and other serious mental illness, and drive its implementation in the NHS.

In October 2013, a ‘Mental Illness and Employment Task and Finish Group’ was established to focus on making policy change a reality.

The T&F Group has made significant progress and it now wishes to share its findings with key stakeholders to continue to raise awareness of the need for change and bring about concrete action.

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**Survey respondent**

“I think any schemes to get mental health service users back to work must be tailored to their specific needs and understand the fluctuating nature of mental illness and the side effects medication can have.”

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“**The problem is that mental health provision very often has no ‘joined up handwriting’ approach and will often keep to their own specialty. Where possible, all individuals should be provided with cross-agency support, or allocated a team of specialists to work in co-ordinating a cohesive strategy based on need, not on cost.”**

Survey respondent

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“It seems to me that permanent unemployment is seen by many in the caring professions as the natural state for people with a diagnosis of schizophrenia and I would strongly challenge that view.”

Survey respondent

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*This survey and report were produced by SANE, with financial support from Janssen. Janssen provided input to the development, scope and design of the survey and report. SANE retain editorial independence and editorial control of the findings of the research and has exclusive ownership of all intellectual property arising from it.*
CELEBRATING SUCCESS
Workstream 1: CQUIN

Workstream lead
Miles Rinaldi
Head of Recovery and Social Inclusion, South West London & St George’s Mental Health NHS Trust

Background
Commissioning for Quality and Innovation (CQUIN) is a national framework which provides financial incentives for local services to meet certain quality and innovation targets. Providers have a range of nationally-set CQUIN targets and are able to choose and develop local CQUINs based on local priority areas.

A number of mental health CQUINs have been developed to drive improvements in aspects of mental health care covering areas including physical health care, medicines reconciliation, smoking cessation training, and recovery-focused mental health services.

Progress
A data meeting took place with members of the T&F Steering Group and the HSCIC in which issues around data viability were discussed, as well as potential problems with incompleteness of data recording (standing at 38%).

A draft CQUIN target has been developed by Miles Rinaldi, entitled ‘Supporting adults in contact with secondary mental health services to gain and retain employment’.

The CQUIN has been produced with the principal aim of supporting adults in contact with secondary mental health services to gain and retain employment. It has three indicators:

1. To ensure 95% data completeness for the employment status indicator from the Mental Health Minimum Data Set (MHMDS).

2. As part of people’s most recent assessment, formal review or other multi-disciplinary care planning meeting, to be asked if they would like help with finding or keeping work. Of those people who say ‘yes’, feedback to be reported on their levels of satisfaction with the support provided.

3. The Trust in partnership with health and social care commissioners, Jobcentre Plus and the voluntary sector to develop, and begin implementing a strategy for the implementation of the IPS approach, to good fidelity, across adult community teams. The aim of the strategy is to achieve a year on year increase in the proportion of adults in contact with secondary mental health services in paid employment subject to the economic cycle.

NHS England is now responsible for the CQUIN’s future direction and implementation.
CELEBRATING SUCCESS

Workstream 2: Clinical Commissioning Groups Outcome Indicator Set

Workstream leads
Miles Rinaldi
Head of Recovery and Social Inclusion, South West London & St George’s Mental Health NHS Trust

Ian Smyth
Commercial Director, Janssen Healthcare Innovation

Background
Despite Outcome Indicators around employment and mental illness being included in the NHS, Public Health, and Adult Social Care Outcomes Frameworks, there were no indicators in the CCG Outcomes Indicator Set to improve employment rates for people with severe mental illness.

In 2013, national bodies, including the Schizophrenia Commission and the Work Foundation, called for a CCG OIS indicator on employment of people with severe mental illness, but the CCG OIS Advisory Committee rejected the indicator, stating that there were challenges in segmenting data at a CCG level, while also questioning whether the issue was within the remit and control of commissioners.

However, the T&F Group felt that the development of such an indicator would enable primary care to better support job retention and the return to employment of people with severe mental illness at an earlier stage. It would also provide a more robust source of data on the employment status of people with severe mental health conditions, which would in turn improve the ability to critically evaluate the effectiveness of employment interventions.

Progress
The T&F Group set out to create a national stakeholder consensus to persuade NHS England to overcome the CCG OIS Committee reservation around a CCG OIS indicator by building a compelling service-user evidenced case for increased health service prioritization, and facilitating national parliamentary and policy discussions.

In December 2013, NHS England announced that a new CCG indicator on employment of people with Serious Mental Illness (SMI) on ‘the proportion of adults in contact with the secondary mental health services in paid employment’ would be included in the 2014/15 CCG Outcome Indicator Set.

The indicator was based on an already established measure currently used within the Adult Social Care Outcomes Framework that was part of the performance framework for mental health trusts until March 2013. The new CCG OIS indicator expands the scope to include all data recording for working age adults in contact with specialist mental health services, rather than just those whose care was managed under the Care Programme Approach (CPA).

The first set of indicator data was published at the time of going to print and shows that the national percentage of adults in contact with secondary mental health services in paid employment has declined from 7.1% in 2012/13 to 5.7% in 2013/14.¹
CELEBRATING SUCCESS
Workstream 3: NICE Quality Statement

Background
The NICE Quality Standard on ‘Psychosis and schizophrenia in adults’ is currently in development, which includes 10 Quality Statements that will act as a key lever in influencing and incentivising mental health commissioning.

The T&F Group recognised that there was an opportunity for the forthcoming Quality Standard to shape commissioning employment support for people with severe and enduring mental illness.

Progress
The Group held a workshop in May 2014 with invited experts who were asked to advise them in the production of a draft Quality Statement. The aim of the workshop was to review the evidence on employment and psychosis/schizophrenia and agree the content and key measurements that could be included in a Quality Statement for the NICE Quality Standard.

Informed by discussions and input at the workshop, a Quality Statement on mental illness and employment was produced and submitted as part of the formal NICE topic engagement exercise process.

In September 2014, the draft Quality Standard was published which included the following statement: “Adults with psychosis or schizophrenia who wish to find or return to work are offered supported employment programmes”.

Task
The inclusion of a Quality Statement on employment in the proposed Quality Standard on Schizophrenia

Workstream leads
Margaret Edwards
Director of Strategy and Communications, SANE

Dr Jed Boardman
Senior Policy Adviser, Centre for Mental Health

Joint Commissioning Panel for Mental Health Guidance
Following the original round table meeting, Jed Boardman and Miles Rinaldi were asked by the Joint Commissioning Panel for Mental Health (JCP-MH) to lead the development of commissioning guidance for health and social care commissioners for mental health employment support services.

The JCP-MH is co-chaired by the Royal College of Psychiatrists and the Royal College of General Practitioners. Representing a collaboration between leading organisations within the health and social care sector, it has worked since 2011 to provide CCGs and other groups with clear and practical guidance on what ‘good’ mental health, addictions, and learning disabilities services look like.

To date, the JCP-MH has produced 17 different commissioning guidelines, and has built a reputation as a source of credible and readable information for commissioners.

The JCP-MH’s new commissioning guidance will examine mental health employment support services. It will be aimed primarily at CCG and Local Authority Commissioners, but will be of use to providers of mental health services. The rationale for developing this new guide is that commissioners and providers alike often lack sufficient understanding of the importance of employment as a key outcome for people with mental health conditions, and the types of support that can be offered to improve such outcomes. In view of this, the new guide will cover the essential facts about employment and mental health and the services that need to be delivered in order to improve the opportunities for people with mental health problems to gain employment. The guide will cover the use of employment support services in both primary and secondary care with a focus on gaining competitive employment along with job retention support. The first meeting of the working group was held in November 2014 and it is anticipated that the commissioning guidance will be published in late autumn 2015.
Given the developments across the key policy levers the time has never been so opportune to prioritise employment and mental health, in particular for people with schizophrenia and other severe mental illness. With this in mind a vital emerging focus for the T&F Group will be to grab hold of these levers and promote implementation: supporting commissioners and mental health services in prioritising employment support.

The T&F Group is considering proposals around the development of a suite of implementation tools and the establishment of a dedicated CCG Outcome Indicator working group to engage with key commissioners and individuals at both a national and local level, to help support best practice and share findings.

It should be noted that answers to Parliamentary Questions by Paul Burstow MP revealed “real and unjustifiable variation” in local employment rates\(^{13}\). Against this background, the T&F Group plans to develop ‘best practice’ case studies with some of the best performing areas which are achieving 20% employment rates.

As a first step, the group plan to host a roundtable event with CCGs to support dialogue among commissioners, and share and review best practice. The roundtable will also help establish which implementation tools will help drive uptake of the indicator across CCGs, and where and how they should be hosted and disseminated.

The T&F Group will also support regional commissioners to engage with commissioners and providers in their respective areas, and ensure the issue is on local agendas through a series of regional meetings currently under consideration by the T&F Group.

The first set of data from the CCG Outcome Indicator was recently published, with it due to be updated every quarter. Future indicators will include a disaggregation by care clusters, providing more information regarding serious mental illness. The Group will benchmark these figures to see how the data fares over time, and to raise awareness amongst commissioners.

“Aside from giving birth to my 15 year old son and studying for a part time Open University degree, being in employment is the best thing that has happened to me since being diagnosed with a mental health condition.”

Yvonne Stewart-Williams, Service user
# MENTAL ILLNESS AND EMPLOYMENT TASK AND FINISH GROUP

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<td>Marjorie Wallace CBE</td>
<td>SANE (Co-Chair)</td>
<td>Marjorie Wallace is the Chief Executive of SANE, which she founded in 1986 in response to her Forgotten Illness campaign in The Times. An investigative journalist, author and scriptwriter, Marjorie has been a respected and credible voice on disability and mental health issues for many years and is regarded as one of the strongest influences on government reforms in mental health. She has won numerous awards for her writing and campaigning and is an Honorary Fellow of the Royal College of Psychiatrists.</td>
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<tr>
<td>Rt Hon Paul Burstow MP</td>
<td>(Co-Chair)</td>
<td>Paul has been the Liberal Democrat MP for Sutton and Cheam since 1997. He has served as Shadow Secretary of State for Health, Shadow Minister for London, Liberal Democrat Chief Whip and Minister of State for Care Services. Paul is currently Chair of the Liberal Democrat Health Backbench Committee. In 2013, Paul chaired the Joint Parliamentary Committee on the Draft Care and Support Bill and he has recently chaired a year-long independent commission on mental health.</td>
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<tr>
<td>Angela Greatley OBE</td>
<td>Tavistock and Portman NHS Foundation Trust</td>
<td>Angela Greatley was first appointed Trust Chair of the Tavistock and Portman NHS Foundation Trust in November 2009. Angela was formerly Chief Executive of the Sainsbury’s Centre for Mental Health, a Fellow in mental health at the King’s Fund, and has experience of working in the NHS in a variety of managerial roles and as a director of commissioning. Angela was awarded the OBE for services to mental health in the 2012 Birthday Honours List.</td>
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<tr>
<td>Ian Smyth</td>
<td>Janssen, Pharmaceutical Companies of Johnson &amp; Johnson</td>
<td>Ian leads on Janssen’s government affairs and policy strategy in the UK for Mental Health. In that capacity he is currently Chair of the Pharmaceutical Mental Health Initiative (PMHI) – an industry collaborative group operating in the UK, and Chair of the Industry and Mental Health Services Collaborative – a partnership between NHS England, The UK Department of Health, NICE and the Association of British Pharmaceutical Industry (ABPI).</td>
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<tr>
<td>Dr Jed Boardman</td>
<td>Centre for Mental Health</td>
<td>Jed is Consultant Psychiatrist and Senior Lecturer in Social Psychiatry at South London and Maudsley NHS Foundation Trust and the Institute of Psychiatry. He is senior policy adviser at the Centre for Mental Health and Lead for Social Inclusion at the Royal College of Psychiatrists.</td>
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<tr>
<td>Margaret Edwards</td>
<td>SANE</td>
<td>Margaret Edwards is Director of Strategy and Communications at SANE. She worked formerly in the Department of Health and Social Security in a range of policy and legislative areas, including mental health legislation and the secure hospitals. At SANE, Margaret is involved in developing its helpline and other services and works with other external partners on policy and other initiatives.</td>
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<tr>
<td>Miles Rinaldi</td>
<td>South West London &amp; St George’s Mental Health NHS Trust</td>
<td>Miles Rinaldi is the Head of Recovery and Social Inclusion at South West London &amp; St George’s Mental Health NHS Trust. Since working within mental health he has established employment services to help people with mental health problems gain and retain employment which have been recognised as models of good practice. More recently he has been working to implement recovery-focused practice across the Trust.</td>
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REFERENCES


13. Data obtained by Paul Burstow MP following a series of parliamentary written questions. Further information can be obtained through the Health and Social Care Information Centre.