

Rethink
Mental
Illness.

The Schizophrenia Commission

Progress report

Five years on



Contents

Foreword	3
The last five years	4
Stigma	5
Secure care	6
Shared decision making	7
Welfare	8
Workforce	9
Housing	10
Black & Minority Ethnic communities	11
Early Intervention	12
Carers	14
Physical health	16
Employment	17
Progress so far	18
Looking forward	18
References	19

Who we are

Rethink Mental Illness is a charity that believes a better life is possible for millions of people affected by mental illness. For more than 40 years we have brought people together to support each other.

Rethink Mental Illness actively campaigns nationally for policy change, and locally for the support needed by people affected by mental illness. We provide services which will help shape lives – leading the way to a better quality of life for everyone affected by mental illness.

Traffic Light System

Throughout this report, you will see traffic light icons which look like this:



For the purposes of this report we have rated progress towards the original recommendations as red, amber or green. We recognise that some recommendations in the report exist in a wider policy / societal context. Many of these factors are complex and opinions on them vary.

To ensure our ratings are objective and measurable, we have analysed progress against the specific recommendations within the report and have not included any broader factors in our assessment.

Foreword

When I started as chair of the Schizophrenia Commission in November 2011, our objective was to establish the practical steps needed to make sure that everyone with psychosis is offered the treatments that we know work best, delivered with kindness and competence.

The fourteen Commissioners brought with them a wide range of knowledge about mental health and by the time that we published *The Abandoned Illness* a year later, we had spoken to over 80 experts, including people who have lived with psychosis, family members and carers, health and social care practitioners and researchers. Thousands more submitted written evidence.

Despite improvements in the understanding of psychosis, we found a broken and demoralised system that did not deliver the quality of treatment that is needed for people to recover. We uncovered appalling statistics and accounts of the care people were receiving. Crucially, we found people clamouring for change and widespread support for the 42 recommendations made by the report.

Just over five years on, this report looks at 11 of the key recommendations and asks: what has changed? Some of the positive developments we identified in 2012 have been built on. Our understanding of the causes of psychosis has continued to improve and with it our understanding of how to help people. At the same time, mental health is more talked about than ever before. That matters because of the impact we know that stigma has, but also because it is the backdrop against which policy and funding decisions are made.

It is encouraging that politicians from all parties are now emphasising that mental health is as important as physical health, and that mental and physical health services should have equal priority. Sadly, this encouraging rhetoric has yet to make a significant impact on the resources available.

I am pleased that, five years on, the recommendations of the *Abandoned Illness* continue to shape the design and delivery of care and treatment for people affected by schizophrenia, not least by influencing the approach of the Five Year Forward View for Mental Health.

However, progress has been far too patchy and too slow.

As this report sets out, people are still not guaranteed access to high-quality, evidence-based treatments of their choice, close to home. Carers, family and friends are often excluded from contributing to meaningful discussions about options. People from Black communities in the UK and those living in the inner cities have a greater incidence of psychosis and services have yet to develop appropriate ways to overcome the disadvantages they suffer. The impact of austerity means that vital services are stretched further than ever, impacting on workforce provision and morale.

In 2012 the Commission pointed out that cannabis use is the most preventable cause of psychosis. Subsequently, evidence has shown that in some areas one quarter of all people developing psychosis would not have done so if they had not been using high potency cannabis. Sadly, there is little publicity around this, and there are virtually no services focussed on helping people give up their drug taking.

Five years ago, we found that although there had been progress in some areas, “no one should claim we can afford to leave things as they are”. That remains far too true today.



Professor Sir Robin Murray
on behalf of the Schizophrenia Commission

The last five years

In 2012 the Schizophrenia Commission published a ground-breaking report called *Schizophrenia – The Abandoned Illness*. It revealed a complex and dysfunctional system that could not deliver quality treatment or support for people with psychosis.

The Commission identified areas across the health and social landscape which were failing people with psychosis and set out a series of recommendations for change. This report looks at the progress which has been made across the sector in the last five years against 11 key recommendations.

Not all the changes have been positive and austerity has had a significant impact. Across the NHS, care teams are struggling with reduced capacity and increasing demand, and in key areas we are still dramatically behind where we need to be. We still see people with conditions such as schizophrenia failed in regard to their physical health; in 2014/15 just 34.8%¹ of people with severe mental illness received the full range of recommended physical health checks.

In employment, three hundred thousand people with a long term mental health problem lose their jobs each year² and a recent Rethink Mental Illness survey showed that 83% of people who have hiring responsibilities would worry that someone with severe mental illness wouldn't be able to cope with the demands of the job. Inequality still remains stark; people from black and minority ethnic communities are four times more likely to be sectioned under the Mental Health Act³, and when in mental health units, black men are three times more likely to be restrained.⁴

There have been improvements too.

Mental health is higher up the political agenda than it has ever been. The Five Year Forward View for Mental Health, a roadmap to reforming the mental health system, has been put in place and the Government has committed to a review of the Mental Health Act. Alongside this, attitudes towards mental illness are also improving, with Time to Change estimating that there are 4.1m people whose attitudes have improved.⁵ Five years ago, we were concerned at the number of Early Intervention in Psychosis services which were being cut.

Thanks to the introduction of the access and waiting times standards in April 2016, 77% of patients are now starting treatment within two weeks.⁶

Now, the sector needs to come together and ensure that this level of quality can be delivered throughout a person's recovery, once they have moved on from Early Intervention services.

From the perspective of Rethink Mental Illness, the Schizophrenia Commission has shaped our policy and campaigning work over the last five years. We also established the 'Innovation Network' forming a network of providers of mental health care and treatment to test interventions in response to the Schizophrenia Commission recommendations. These providers worked together to design, implement and evaluate a number of interventions; smoking cessation, collaborative care planning and peer support.

Looking to the future, there are opportunities ahead; we know more about schizophrenia than ever, and technological developments are ensuring that evidence of what works can be shared more easily and widely. This is a prime time for innovation and improvement.

Rethink Mental Illness is committed to continuing to improve the lives of people severely affected by mental illness. We are pleased that many of our programmes are leading the way in delivering the recommendations of the Schizophrenia Commission.



Danielle Hamm

Associate Director of Campaigns and Policy,
Rethink Mental Illness

Stigma



The Schizophrenia Commission said: “We commend the Department of Health, the Big Lottery Fund and Comic Relief for investing in Time to Change (www.time-to-change.org.uk) and recommend continued investment in anti-discrimination programmes and other public education initiatives that deliver accurate messages about mental health and mental illness with the aim of changing attitudes and behaviour. These need to address the elements of stigma and discrimination which are specific to people affected by schizophrenia and other psychotic illnesses.”

In 2012, the Schizophrenia Commission found that 87% of service users reported experiences of stigma and discrimination, and urged the sector to tackle this issue.⁷ The Time to Change campaign, run jointly by Rethink Mental Illness and Mind, has achieved significant improvement in this area. Amongst the general public, the overall trend of attitudes between 2008 and 2016 changed for the better by 9.6%.

People who have a mental health condition also reported a reduction in the levels of stigma which they experience. Average levels of reported discrimination fell from 41.6% to 28.4%. Some of the biggest reductions in discrimination have come from the changed behaviour of family and friends.⁸

However, while general public attitudes have shifted, 1 in 3 people using mental health services still report experiencing stigma and discrimination from within those services.⁹ Time to Change conducted a small pilot project of workshops within mental health services, delivered by people living with mental illness.

The pilot project led to improvements in the attitudes and intended behaviours of mental health professionals, as well as changes in actual behaviour to improve the experience of people using mental health services.¹⁰ It also helped thousands of mental health professionals to begin conversations about tackling stigma and feel more comfortable discussing their own challenges with mental health. This pilot has demonstrated that specific focus is required to facilitate progress within this area, however, without continued funding for this work it is unlikely to become embedded as standard practice.

Over 1,200 Rethink Mental Illness campaigners contacted their local MPs calling for the passing of the **Mental Health (Discrimination) Act 2013**.

This landmark Act has now removed discriminatory provisions in legislation relating to jury service, MPs, and company directors, following campaigning work by Rethink Mental Illness and others.



Shaun's story

If you've never met someone with schizophrenia, I can see how you might imagine it's something scary like in the movies, but even if you were to judge someone on a diagnosis, even Batman said "It's not who I am underneath, but what I do that defines me".

People don't think someone down their road who works in Sainsbury has an illness like this. The biggest challenge in my life is stigma when I talk to people about my condition, I always start with the symptoms, not the diagnosis.

I've spent a lot of time explaining what my illness is and isn't, to employers, friends and even family. Once people hear about my diagnosis I feel like they look at me and my behaviours differently. It's sad really, and it can make the condition worse.

It's just a word but 'schizo' can have really negative connotations. But I know that people have managed to reclaim negative words in the past and I want people to really rethink the word and what it actually means for the person who has been given this diagnosis.



Secure care



The Schizophrenia Commission said: “We recommend that the Department of Health, with involvement from the Ministry of Justice, requires the NHS Commissioning Board to develop a national commissioning strategy for secure care with the aim of rationalising definitions of security and establishing recovery-focused care pathways through secure care. Savings identified as a result of this exercise should be reinvested in strengthening community based provision.”

The findings of the Schizophrenia Commission relating to secure mental health services informed the recommendations of the Five Year Forward View for Mental Health in 2016.¹¹ This resulted in the creation by NHS England of a new Secure Care Programme,¹² which aims to improve the experience of people in secure services, including reducing the length of stays and ensuring people can be treated closer to home.

During 2016/17 the NHS England Secure Care Programme carried out the first national audit¹³ of adult secure mental health services, which provided new information about who is using services, where and for how long. It showed that in areas with more robust community forensic teams, people spent less time in hospital, leading to better outcomes for individuals and cost-savings for the system.



Spotlight on Recovery and Outcomes

The Recovery and Outcomes programme,¹⁵ delivered by Rethink Mental Illness, is a national network of service users, staff and commissioners from secure services that aims to improve the recovery focus of secure mental health services and wider policy and practice. Nine Groups meet every three months, across England. The Recovery and Outcomes Groups are focused on a specific theme or topic, and include presentations from service users and staff, group discussions and feedback.

For the past five years the programme has supported people to:

- Share journeys of recovery
- Share best practice and learn from each other

And:

- Delivered service-user led improvements in services
- Shaped national policy including the NHS England Secure Care Programme and the Ministry of Justice Secure Care policy.

As a result, a new model for community forensic services has been developed in partnership with those using secure services and clinicians, which will be piloted in four areas of the country in 2018. This new model requires providers to develop more and better community care teams and to have greater peer support, better 24/7 crisis care, employment and education opportunities, and improved support for carers, family and friends.

Alongside these improvements to community services, NHS England is also piloting ‘New Care Models’¹⁴ for inpatient services, which aims to reduce length of stay and the number of out-of-area placements.

However, a continuing challenge is the lack of available, appropriate step-down supported housing for people who are ready for discharge, which causes lengthy delays. Stays in secure care cost on average £17,890 a month, which means that delays in discharge from secure care are costing vast amounts. Even the most expensive form of supported housing costs approximately £1000 a month.



The Schizophrenia Commission played an important role in highlighting the case for rebalancing investment between secure care and effective community provision for people with schizophrenia and other forms of severe mental illness.

NHS England has now launched the New Models of Care programme which has seen a group of providers taking over responsibility for the local commissioning of secure provision.

This is creating the right financial and clinical incentives to avoid out of area placements, reduce lengths of stay and reinvest savings in developing locally based services.

Paul Jenkins,
Schizophrenia Commission



Shared decision making



The Schizophrenia Commission said: “We recommend that the Department of Health, as part of its current review of shared decision-making, commits to giving people using mental health services an element of choice as to where they are treated, with a particular focus on guaranteeing a right to a second clinical opinion and allowing people and families a bigger say in choosing a lead professional for their care.”

The Schizophrenia Commission called for shared decision-making to be the ‘cornerstone of practice’,¹⁶ with individuals having a vital role to play in building their care and treatment plans. Progress towards this recommendation has been supported by references to patient involvement in care within the Five Year Forward View and the Care Act.

Case law has also played an important role in shifting attitudes towards patient involvement from professionals and providers. *Montgomery v Lanarkshire Health Board* (2015)¹⁷ was a landmark judgement by the Supreme Court which provided a common law basis for the inclusion of patients in decisions about their own care and treatment. But to date, development of patient involvement has been patchy.

In 2016, the CQC *Better Care in My Hands* report used a comprehensive literature review, patient surveys and other data to assess how patients had been involved in their care.¹⁸ The report demonstrated the positive impact of collaborative involvement and the vicious cycle that a lack of patient involvement can create, leading to worse outcomes which make involvement harder.



Of the 3,836 care records of people detained under the Mental Health Act in 2014/15 reviewed by the CQC, 25% had no evidence that patients had been involved at all in developing their care plans, and 32% (964 of 3,000) of the patient records examined did not include a capacity assessment for medication when someone was admitted to hospital.¹⁹



Spotlight on: The Innovation Network’s care planning pilot

Rethink Mental Illness’ Innovation Network recognised that increasing the involvement of individuals who use services in their own care planning and risk assessments could lead to better recovery outcomes, especially for those in secure services.

An evaluation was commissioned to assess the impact of a more collaborative care planning approach and whether it would lead to better self-reported recovery outcomes from people using secure services, and more recovery-focused care plans.

The evaluation demonstrated that more patients were involved in writing and shaping their care plans, and as such felt more empowered, more confident and they had a clearer understanding of the steps required to move on.

One participant in a medium secure unit explained “The care plan provides a good summary of your recovery: where you have been and where you are going. It tells me why I am here, how long I will be here, and where I am going next.”

Welfare



The Schizophrenia Commission said: “We recommend that the Work Capability Assessment process is amended for people with schizophrenia and psychosis to require the Department for Work and Pensions to seek information from health professionals to guide decisions rather than requiring potentially vulnerable people to navigate complex systems in order to provide it themselves. The same principle should be built into plans relating to any qualifying assessment for the new Personal Independence Payment.”

The Work Capability Assessment (WCA) continues to be a cause of severe distress to people affected by mental health problems and the concerns that the Commission had that these problems could be mirrored in the Personal Independence Payment system proved to be accurate.

Although some claimants with long term conditions are now exempt from reassessment following a Government announcement in 2016,²⁰ too little has changed.

The *‘It’s Broken Her’*²¹ report by Rethink Mental Illness recently found that claimants, including those affected by schizophrenia and psychosis, found the process complex and extremely stressful, negatively impacting their health.

The most recent statistics show that 60% of fit for work decisions that are taken to tribunal are overturned.²² This shows how often the system is getting these assessments wrong.

In 2014, an Upper Tribunal found that the WCA places people with mental health problems at a ‘substantial disadvantage’ and urged the Department for Work and Pensions (DWP) to trial changes to the process.²³ However, these trials have not taken place. In 2016 the DWP published the *‘Improving lives: The Work, Health and Disability Green Paper’*²⁴ which included proposed changes to the WCA but missed a significant opportunity to reform the system for people with mental illness.

Jane’s story

I waited months for an assessment and then the person carrying it out was quite rude and had little knowledge of mental health issues. She seemed to make her own assumptions and had clearly not even looked through the evidence. Eventually I got a letter stating I was not able to get PIP, so I asked for mandatory reconsideration.

That was turned down, so I went to the tribunal, where I was eventually awarded PIP. All of this took about a year, and then I had to go through the entire process again. This has caused me a great deal of stress. It’s made my mental health decline a lot as I have been trying to cope with everything.

Because my income was reduced dramatically I have been really struggling and will probably lose my home. This has led to my depression worsening to the point that I was frequently self-harming.

It is frustrating that, five years on from the Schizophrenia Commission, we have yet to see significant reform with regard to welfare and employment.

The problems we highlighted with the Work Capability Assessment still exist, which means that many applicants are wrongly denied the support they need, or risk their health fighting for it.

We need a system designed with people with severe mental illness in mind and that genuinely listens to them.

**Martin Knapp,
Schizophrenia Commission**

Workforce



The Schizophrenia Commission said: “We recommend that professional and educational bodies should review their curricula in the light of our recommendations. We strongly support the RCGP’s recommendation to extend GP training in respect of mental illness. We recommend that Health Education England and the General Medical Council should urgently review how medical students could spend more continuous time in their psychiatric placements and have greater emphasis placed on mental health throughout their training and Deans of Medical Schools should positively promote an interest in mental health.”

The Royal College of General Practitioners is still campaigning to extend the time spent in specialist GP training from three to four years in order to spend more time training on mental health.²⁵ Additionally, the General Practice Forward View stated that from April 2016, CCGs should be able to install a mental health professional in GP settings.²⁶

Since the Schizophrenia Commission published its recommendations, low numbers of doctors taking on psychiatry posts and a high number of vacant positions have led to increased efforts to get more junior doctors into psychiatry placements,²⁷ with the aim to increase the number of foundation psychiatry posts from less than 5% of all posts to 22.5% by the end of 2017.

There are currently 11,400 medical posts in mental health services of which 5,400 are consultants. Of these 1,400 (12%) are vacant including 700 (13%) consultants.²⁸

In 2017, Health Education England published their ‘Mental Health Workforce Plan’. Although this ambitious strategy set out aims to recruit 19,000 additional staff members by 2020,²⁹ what it lacked was clarity about *how* this would be achieved in practice. It also focussed heavily on psychiatry, and was criticised for failing to build adequate plans to develop other areas of the workforce; social workers, psychologists, therapists and experts by experience.

It did however emphasise that to ensure that these roles meet the needs and expectations of the patient population, advertised posts require staff to demonstrate partnership working and co-production principles.³⁰ Health Education England should continue to work on development plans for the workforce alongside partners representing the full range of roles.

To ensure that these roles meet the needs and expectations of the patient population, advertised posts require staff to demonstrate partnership working and co-production principles.³¹

This strategy also highlighted the context in which the workforce is attempting to deliver the Five Year Forward View for Mental Health; more mental health nurses are currently leaving the profession than joining, with a turnover of -4%, compared to +2% for adult nursing.³² The impact of Brexit on this turnover will also have an effect on the ability of the sector to meet the recommendations.



As Chief Executive of South Staffordshire and Shropshire Healthcare NHS Foundation Trust, I have seen how the mental health workforce has been affected in a number of ways by the Abandoned Illness report. As a trust we embarked on a journey of understanding how we could address some of the key issues in the report. We worked closely with Rethink Mental Illness and other partners to agree a focus on improving healthcare within our forensic mental health services and have made significant improvements in measures of physical health improvement (such as weight loss and smoking cessation). Service users and staff have worked together to embed changes in co-produced recovery college programmes.

We have also developed an independent programme of work around physical health within our adult mental health services: our physical health pathway is up and running and we have been working with a cross regional group to look at improving measurable health outcomes. We are proud of our achievements to date, but recognise there is still a long way to go to get true parity of esteem for people with schizophrenia that is grounded in real partnerships with primary healthcare and general practice.

Neil Carr
Schizophrenia Commission



Housing



The Schizophrenia Commission said: “We recommend that Health and Wellbeing Boards ensure the housing needs of people with severe mental illness are adequately addressed.”

Historically, the links between housing and health have been largely ignored by government, even as housing overall has seen increasing political attention in recent years, highlighted recently by the rebrand of the Department for Communities and Local Government to include a focus on housing. The lack of awareness of the importance of housing for health is demonstrated by numerous issues with the supply and commissioning of affordable supported and step-down housing for mental health.

The National Housing Federation estimates that there will be a shortfall of 35,000 supported housing places by 2020/21.³⁴

There are many examples of good practice across the country where CCGs, Local Authorities and Mental Health Trusts are working together to jointly plan and commission housing and supported accommodation for people with mental health problems. For example, specialist step down housing such as Tile House in London has been used to move people who are homeless on from hospital and ensure their housing needs are supported.

Recent work by the Department of Health has identified that a lack of suitable housing can be one of the major issues in leading to Delayed Transfers of Care for people being discharged from mental health inpatient units. Sheffield and Bradford have reduced bed occupancy and out of area placements by commissioning supported housing and specialist housing discharge arrangements.

**Jonathan Phillips, Schizophrenia Commission,
as advised by Mark Trewin,
Service Manager Mental Health,
Bradford Council**

In October 2017 the Government published proposals³³ to devolve funding of short-term supported housing (stays of less than two years) to local authorities. This will remove this type of supported housing from the welfare system entirely. Local authorities will assess supported housing needs as well as current provision and form supported housing strategic plans.

When local authorities develop these plans, they will be asked to do so with a range of partners, including Health and Wellbeing Boards. However, the consultation contains no detail on how Health and Wellbeing Boards should be consulted or the extent to which they can influence local authorities.

Under this proposed system, short-term mental health supported housing will be commissioned from a finite pot of money and people with mental health problems will be competing with those with other problems (e.g. homelessness or addiction) to access supported housing. This will make accessing mental health supported housing more challenging and less secure.

After sustained campaigning Rethink Mental Illness were successful in ensuring that the previously proposed Local Housing Allowance (LHA) cap to Housing Benefit will not apply to tenants in mental health supported housing. We will continue to work with the mental health sector and the Government to ensure that the revised policy does not apply to mental health supported housing as proposed.

Our hope is that Housing Benefit will continue to cover rents for the vast majority of mental health supported housing tenants, with a new model introduced outside of the benefits system for very short-term and emergency accommodation. The timeframe for this model should be defined in weeks, not years.

Black & Minority Ethnic communities



The Schizophrenia Commission said: “We recommend that Health and Wellbeing Boards ensure there is a strategy in place which specifically addresses the needs of minority ethnic groups in their communities. The strategy must include an emphasis on mental health promotion as well as providing personalised care which must be culturally competent.”

The Schizophrenia Commission was particularly concerned with the lack of mental health promotion within Black and Minority Ethnic communities, the barriers which prevented access by these groups to mental health services, and the poor outcomes experienced when using these services.

Detentions amongst BME people are also rising disproportionately compared to the general population.³⁵ The review of the Mental Health Act, announced in Autumn 2017, has a specific focus on the over representation of black men as being detained under the Act, and aims to understand and make recommendations to address the structural reasons which lead to this.³⁶

Black and Black British groups are four times more likely to be detained in secure mental health care than White British groups, and six times more likely in London.³⁷

A survey commissioned by Time to Change of people from minority ethnic groups with mental health problems found that 28% of Black Caribbean and 31% of African respondents reported that they had directly experienced racism within services during the preceding 12 months.³⁸ This stigma and discrimination means that people are less likely to access mental health services, and are therefore likely to make their first point of contact during crisis; often in relation to the police.



Spotlight on 300 Voices

Time to Change launched the ‘300 voices’ project to improve the outcomes of young African and Caribbean men in inpatient mental health services.

This pilot project was undertaken in the West Midlands, and developed a peer-led approach, involving people with lived experience from the BME community, mental health professionals and the police.

Findings from this pilot show this collaborative approach can lead to:

- Professionals who took part felt the project improved their knowledge, and helped them to feel more confident in working with young African and Caribbean men with experience of mental health problems.
- Young African and Caribbean men who attended the workshops reported feeling more confident to speak about their own mental health.³⁹



Five years on from the Schizophrenia Commission, we are still witnessing the shocking treatment of people from Black & Minority Ethnic communities who have been diagnosed with a mental illness.

Unfortunately, Black voices are rarely heard at decision-making tables, and more needs to be done to ensure this group is heard, particularly with regards to the review of the Mental Health Act, and beyond. The high rate of detentions amongst this population is of grave concern and warrants robust action to ensure earlier intervention rather than access to services mainly at the point of crisis.

Black Thrive works to reverse this imbalance whereby the voices from African and African Caribbean communities are central in coproducing, shaping and influencing the design and commissioning of local mental health services.

Jacqui Dyer, Black Thrive



Early intervention

The Schizophrenia Commission said: “We recommend that all Clinical Commissioning Groups commission Early Intervention in Psychosis services with sufficient resources to provide fidelity to the service model. It is crucial that the NHS Commissioning Board holds local commissioners to account for this and we recommend that early intervention services are included in the NHS Commissioning Outcomes Framework.”

Early Intervention in Psychosis has transformed the lives of thousands of young people in England. These services are aimed at people who are experiencing their first symptoms of psychosis, who will be supported by a multi-disciplinary team of health and social care professionals. Evidence shows that this is the best model for helping young people recover from a first episode of psychosis. These services dramatically reduce the risk of a young person taking their own life, and save the NHS tens of millions of pounds each year.

In 2014 Rethink Mental Illness published the Lost Generation report, which looked at the troubling impact on young people of cuts to early intervention services. This report raised the profile of these services and, as a result, they are one of the subjects of the first ever mental health waiting time and access standards in the NHS.

The introduction of these standards was a landmark, and goes a long way towards meeting the recommendation within the *Abandoned Illness*.

Other approaches to early intervention are also developing, and currently a pilot project for ‘Open Dialogue’ is being trialled in several locations in the UK. This approach originated in Finland, and focusses on providing immediate help for people in a crisis, building on the support of an individual’s established social network (family, friends, co-workers etc.), embedding a multi-disciplinary team within this network, developing a common language to discuss symptoms, and a shift away from medication.⁴⁰

Luke’s story

I had been to university but I dropped out. It was at that point that I had a major breakdown when I went missing for over 24 hours. That was what alerted my family to the fact that something wasn’t right.

From there mum and dad suggested that I talk to the mental health team, and it was through them that I was put in touch with the Early Intervention Team.

Through the Early Intervention in Psychosis Team I was put with my first case worker, and yeah that really helped me understand what I was feeling, the build up to it. Understanding what I had been through and just being able to talk about it.

In itself that was a very different thing, something I hadn’t done before. So it was quite reaffirming to be able to talk about it in a safe way and with people who understood.

Early Intervention in Psychosis (EIP) services are one of the big successes of recent years. These services have demonstrated that when sufficiently resourced, they can have an overwhelmingly positive impact on service user outcomes and can deliver savings to the wider health system.

The recent EIP access standard was established to ensure EIP services continue to deliver high quality services. Since the introduction of the standard, not only can those presenting to EIP services with a first episode of psychosis expect to be seen within two weeks, but all service users and their families should have access to the full range of NICE recommended interventions.

Work now needs to be undertaken to ensure that all those with psychosis beyond those with a first episode, have timely access to high quality evidence based care including psychological therapies.

Alison Brabban,
Schizophrenia Commission



I didn't get the right treatment and felt like I was in 'pass the parcel'. For years I'd just be bounced around with endless horrible assessments and no help. In the end, I waited for seven years before I finally got access to the Early Intervention in Psychosis team.

With their support, I have gone from being sectioned to finishing my masters in Public Health. I now have a job as a researcher.

Kerry, campaigner for Rethink Mental Illness



The Five Year Forward View for Mental Health included a specific recommendation on early intervention, targeting 50% of people experiencing a first episode of psychosis to access an evidence-based care package within two weeks of referral, rising to a 60% target by 2020/21.

In the vast majority of areas this target is being met, with 77% of people now starting treatment within two weeks.



Carers



The Schizophrenia Commission said: “We recommend that Clinical Commissioning Groups and local authorities commission an appropriate range of services to support the needs of carers of people with schizophrenia and psychosis, including information and advice along with arrangements for respite care.”

In the last five years there have been significant developments in support for carers of people with mental health problems, including schizophrenia. The Triangle of Care approach which emphasises the interconnected relationship between services, service users and carers has grown significantly since its launch in 2010 and has been put into practice by numerous trusts.

The Care Act in 2014 also recognised carers in law for the first time, requiring local authorities to assess a carer’s needs and support as a legal right. However, these policy changes will only go so far in terms of facilitating real change for carers, and the experiences of people across the country do not seem to have seen this impact.

In 2016 the Government started work on a new carers strategy compiling experiences from carers and professionals, but as of December 2017 this had not been published.

The NICE guidelines for carers of people with schizophrenia were updated in 2014 with more emphasis on assessing the carer’s needs separately and advising carers of their statutory right under the Care Act 2014.

Although there has been considerable progress in carer support since the commission, it is clear there is still work needed to ensure appropriate support for carers of people with schizophrenia.

The Schizophrenia Commission report recommended that specialist services for carers for people with psychosis should be commissioned and that respite care should be offered. In reality, specialist services for carers which can give advice on psychosis, have been cut.

There is the “Triangle of Care” concept (carers prevent hospital admissions) but cuts mean that there is less support for the service user and that carers fear that time spent talking to them will cut into contact time for their loved ones, as dedicated support and advice for carers is not there.

Respite is not something which is available; there have been small grants to foster well-being but these have got smaller and more difficult to access and rely on the carer being able to make time available themselves away from the caring role. This is a recipe for a perfect storm when carers are no longer able to cope...

Frances, Carer

I realised that if I was going to be a long term carer, I had to look after myself at the same time. Care is hidden – it goes on behind closed doors. Those who care for family or friends often don’t see themselves as carers, so it’s very important for them to have support.

Eleanor, Carer

I was a carer and was so appalled by the treatment offered to the person I loved that I proposed to Rethink Mental Illness that they set up a Commission on Schizophrenia. It was wonderful that they agreed, set it up and provided the research and secretariat needed to produce a first rate report.

I have been disappointed that support to carers has been inconsistently offered over the last five years, despite the Schizophrenia Commission recommendation. I am now chairing Twining Enterprise which (in line with the Commission's report) supports people with mental health problems into work in London.

Liz Meek, Schizophrenia Commission



A carer's story

After several years of being unable to help my former partner (as we did not know where he was living), earlier this year my daughter used a tracing agency, who found out where he lived and we managed to get him to open the door to us – he had been living, apparently unsupported, in filth and squalor in a Housing Association flat with no oven and no floor coverings.

He had been in a deep depression for more than five years, not washing or changing his clothes, and would not open his door to callers, only going out by taxi every few days to get cigarettes and food – the photos my daughter took of his flat are truly shocking.

We managed to get him to re-engage with the Mental Health Services and helped him to secure supported housing – for the first time since he became ill eight years ago, he now appears to be stable: if he were to lose the supported housing now, it could have catastrophic consequences for him.”



Physical health

The Schizophrenia Commission said: “We recommend that each mental health provider promotes the use of clinical tools to support the physical health needs of people with schizophrenia or psychosis on antipsychotic medication, and ensure that these are visible in every mental health ward in the country. These include the Lester UK Adaptation – Positive Cardiometabolic Health Resource. We recommend that each mental health provider works with the local Director of Public Health to ensure that there is targeted smoking cessation provision for smokers with schizophrenia and psychosis, with guidance from Public Health England.”

The Schizophrenia Commission highlighted the continued overlap between enduring mental and physical illness, and the need for more work in this area to increase the life expectancy of people with schizophrenia.

In 2014/15 just 34.8%⁴¹ of people with severe mental illness on a GP register received the full range of physical health checks.

Rethink Mental Illness successfully campaigned for the first ever national programme for improving the physical health of people living with mental illness, known as a CQUIN.



Spotlight on The Innovation Network's smoking cessation pilot

People with mental illness still die 15 to 20 years earlier than the general population. One of the contributing factors to this disparity is related to the high rate of smoking among people with a mental illness. Through the Innovation Network, we piloted an approach aimed to integrate smoking cessation support within existing mental health care settings. Across the pilot sites we saw positive results.

There is ample evidence that people with mental illness want to give up smoking, and can do so with the right help. Overall, the range of smoking cessation initiatives taken by the providers involved in the Innovation Network pilots have led to:

- a reduction overall in those who identify as a 'smoker'. Some organisations had rates as high as 78% before the pilots, down to 23% afterwards,⁴³
- staff feeling more confident about sharing smoking cessation information (twice as many smokers have been given smoking cessation information).

This now means mental health services will only receive full funding if they measure blood pressure, weight, smoking, glucose and cholesterol levels during consultations and can demonstrate follow-up of this data. To support this, a series of tools for health professionals was developed which have now been endorsed by the Royal College of GPs, the Royal College of Nurses and the Royal College of Psychiatrists. This included support materials for the Lester Tool (a simple flowchart for identifying and treating risks to physical health in patients with psychosis receiving antipsychotic medication).

On the side effects of medications, recently introduced drugs (aripiprazole and lurasidone)⁴² have been shown to have a lower likelihood of weight gain in comparison to more established medication, hinting at a more positive future for the physical health of people diagnosed with schizophrenia. One major challenge is that data has not been published on this area since 2014/15, and this prevents any understanding of the impact of these changes on patients, and hinders attempts to support additional efforts where the need is greatest.

I think we have seen a shift in mental health professionals' attitudes towards physical health. They are taking more responsibility in managing both the physical and mental health of patients and feel more empowered to have difficult conversations about smoking, weight and exercise. However, too many people are still falling through the gaps, including not being offered regular screening for a wide range of preventable conditions. Cultural and behavioural change is difficult but we know it can be done. Until it happens across the board, we will keep seeing poor outcomes for patients.

Lade Smith,
Schizophrenia Commission

Employment

The Schizophrenia Commission said: “We recommend that all NHS Mental Health Trusts and other providers adopt the Individual Placement and Support (IPS) model and ensure that employment support is effectively integrated with clinical services. We believe such support may be best provided by voluntary sector organisations being co-located with clinical teams. Outcomes will also be improved where Mental Health Trusts work closely with Work Programme providers.”

Following the Schizophrenia Commission, the Five Year Forward View for Mental Health also recognised the benefits of the Individual Placement and Support model; (a person-centred approach which supports those severely affected by mental illness into employment) and recommended a doubling in access to it, enabling people with severe mental illness to find and retain employment.⁴⁴

An evaluation of the IPS model by the Centre for Mental Health which took place between 2015 and 2017 highlighted examples of good practice, such as embedding employment specialists in Early Intervention in Psychosis services, or employment services working alongside the Department for Work and Pensions, or the Third Sector.⁴⁵ This provides a useful analysis of the critical factors required for success within IPS services and can therefore support future expansion.

The wellbeing of people with mental illness in the workplace has also shifted further up the political agenda. In 2017, the Prime Minister announced an Independent Review, led by Paul Farmer and Lord Dennis Stevenson into Mental Health and Employment.

This review revealed that the UK is facing a huge mental health challenge at work; highlighting the human cost of poor mental health in the workplace, and the related impact on society, the economy and Government. Employers are losing billions of pounds because employees are less productive, less effective, or off sick.⁴⁷

Rethink Mental Illness commissioned One Poll to seek views from 500 staff with hiring responsibilities.⁴⁶ The poll showed that:

- **over half (54%) of bosses wouldn't know how to support someone with a severe mental health condition, like schizophrenia, at work.**
- **68% of people who can hire staff would worry someone with severe mental illness wouldn't fit in with the team**

Five years on, I've maintained my Thames Reach Homelessness Charity employment, which my Care Co-ordinator first supported me to apply for, throughout application and interview processes, with openly declared schizoaffective diagnosis; and thirteen years of sickness benefit. During my employment, SLAM-South London and Maudsley Psychiatric Hospital NHS Trust Community Mental Health team, has helped me maintain my employment, during ongoing mental health relapses, including imprisonment.

I'm now managed by a SLAM Community Psychiatric Nurse, who works within the collaborating partnership of 3rd Sector GP Plus, Lambeth Hub mental health professionals and is supporting me to stand at the 2018 Lambeth Local Election. Lambeth Hub utilises Lambeth Mosaic Clubhouse mental health employee peers to administer their administration. My work at Thames Reach's 'Waterloo Project' hostel, entails working collaboratively with SLAM Psychologists and Psychiatrists, in a Psychologically Informed Environment (PIE) approach, which now also incorporates constructive supervised employment of Peer Mentors.

Yvonne Stewart-Williams, Schizophrenia Commission



Progress so far

Progress against the 11 key Schizophrenia Commission recommendations reviewed by this report has been patchy. Some areas have seen real improvements, but in others encouraging policy developments have not gone far enough or have yet to lead to substantially improved outcomes. Unfortunately for some areas there has been little or no progress at all.

More people are accessing high-quality early intervention in psychosis services than ever before. Secure services are benefitting from a focussed NHS England programme, a recent audit review and updated service specifications. Additionally work to tackle stigma, including Time to Change, is having a positive impact on attitudes, with more people feeling comfortable to talk about their own mental health and to support others.

In a greater number of recommendations, there has been slow progress. People with mental illness are still dying 20 years earlier and despite interventions such as the CQUIN programme to improve monitoring, a lack of regular published data is undermining progress. Clinicians have begun to recognise the benefits of involving people in their own care, but this varies greatly across settings and is not consistently offered to people at all stages of their recovery. Although national policies to involve and support carers have been developed, family members and friends too often

experience being excluded from important conversations. Successful programmes which support people severely affected by mental illness into employment have been recognised and expanded, but this group is still much less likely to be employed than the wider population.

Unacceptably, there remain several areas where the injustices highlighted by the Commission remain largely unaddressed. Despite a welcome recognition by ministers of the particular challenges faced by black and ethnic minority people with mental illness, that comes in the context of a dramatic rise in detentions that has disproportionately affected black people. The workforce continues to struggle with a high turnover, and the plans for development do not go far enough to ensure a strong, sustainable foundation upon which to deliver high-quality, evidence-based care. People with severe mental illness continue to face obstacles to get the support they need from the welfare system, with many reporting that the application and assessment process has a negative impact on their mental health. Likewise, current funding proposals put mental health supported housing at risk and, if carried out, could have a knock on impact on health services as well as the individuals affected. These examples show again what the Commission recognised: that the responsibility for making sure that people with psychosis get the help they need does not sit only with the Department of Health or the NHS.

Looking forward

When the *Abandoned Illness* report was published, the NHS was in a state of flux. The Health and Social Care Act, impact of the recession and austerity, and lack of parliamentary focus on mental health in the years immediately following the report meant progress was slower than it should have been.

But momentum is building and the next five years offer new possibilities. The Five Year Forward View for Mental Health gives much needed impetus and funds for innovation, research and patient involvement to improve care, opening up opportunities for patients, carers and staff to do more to shape better services. As we approach the mid-point of the Forward View, it is vital that we plan beyond 2020/21 and consider the funding needed in the long term.

The Independent Review of the Mental Health Act is a rare opportunity for change that must be seized. Mental health legislation and the complex web of guidance, practice and

culture that surrounds it should safeguard the rights of people with psychosis and others with severe mental illness when they are at their most vulnerable. The challenge will be not only to get the review right by listening closely to those with lived experience but also to create the public and political engagement that will ultimately be needed to drive through reform.

As Rethink Mental Illness, we are proud of the role we have played in the Schizophrenia Commission and our contributions towards the progress made against the recommendations. Yet the real successes there have been should not obscure the fact that progress has been too slow in many areas. It is encouraging that the pace of change has increased but there is much work left to do so that policy changes impact those they are intended to help and that the needs of people with psychosis are understood across all government departments.

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