



Lost Generation

Why young people
with psychosis are
being left behind, and
what needs to change.

Who we are

Rethink Mental Illness is a charity that believes a better life is possible for people affected by mental illness. For more than 40 years we have brought people together to support each other. We run services and support groups that change people's lives and we challenge attitudes about mental illness.

The IRIS Network is a group of mental health experts and professionals who support the promotion of Early Intervention in Psychosis (EIP). First formed to support the National Early Intervention Programme (2004-2010), this network brings together elected Early Intervention regional leads to share issues and solutions.

Contents

Summary	1
Foreword	2
Psychosis and young people	3
Facts and stats about Early Intervention in Psychosis services	4
Why Early Intervention in Psychosis is so important	6
Tackling inequality for mental health	9
Early intervention under threat	10
Recommendations	14
Call to Action	15
Protecting young people: what politicians need to do now	16
References	17

Summary

Early Intervention in Psychosis (EIP) services help young people aged 14-35 to recover from a first episode of psychosis, and to gain a good quality of life. They support more than 10,000 young people each year.

EIP care significantly improves a young person's prospects of recovering from psychosis. It also reduces the likelihood that they will relapse, or be detained under the Mental Health Act, potentially saving the NHS £44million each year through reduced use of hospital beds.¹ Early intervention also reduces the risk of a young person taking their own life, from up to 15% to 1%.²

However, many EIP services are struggling to maintain high levels of care, and are facing an uncertain future, because of cuts to funding. Where services do exist, many young people are facing unacceptable delays in accessing care. This seriously affects their chances of recovery, and increases the likelihood of them developing a lifelong illness.

As a result, we are at risk of losing a generation of young people whose recovery from mental illness is being jeopardised – tens of thousands of young people who, with the right support, might otherwise have good quality of life and play a meaningful role in society.

This report presents new evidence from the front line about the extent of cuts to resourcing and budgets, and the negative impact on EIP services and the young people they support.

What we found:

- 50% of EIP services say their budget has decreased in the past year, some by as much as 20%.
- 58% of EIP services have lost staff over the last 12 months.
- 53% say the quality of their service has decreased in the past year.
- Many young people face unacceptable delays in accessing EIP services, greatly reducing their chances of recovery.

What we recommend:

- Young people experiencing psychosis need guaranteed access to EIP support. The Government must introduce a maximum waiting time of 28 days for accessing EIP services from the point of referral.
- NHS England must make provision of EIP services a key priority for commissioners. To achieve this, it should design CQUINs³ and other incentives to ensure local commissioners reward good quality EIP services.
- Clinical commissioning groups must ensure that they commission the full EIP model,⁴ including specialist employment and physical health care support.

Foreword

It is nearly 13 years since Early Intervention in Psychosis (EIP) services were widely introduced across the UK. In that time EIP has become established as one of the most effective, popular and innovative service models in mental health.

Few services can match EIP for clinical and economic outcomes. There is a wealth of evidence which shows that early intervention significantly improves people's prospects of recovery, and reduces the likelihood of them relapsing or taking their own life.

Early intervention also offers valuable long term savings to the NHS by reducing the dependence on other mental health services. People who have EIP support are more than 20% less likely to be legally detained in hospital under the Mental Health Act in the first two months of their illness.⁵

But the reality is that without adequate funding, EIP services cannot continue to offer the wide-ranging support for young people that they aspire to. It is therefore deeply worrying that many EIP teams say they are struggling to maintain high standards of care in the face of significant cuts to resources.

In this new survey of EIP services in England, carried out by the IRIS Network and Rethink Mental Illness, 50% of services said their budget has been cut in the past year, sometimes by as much as 20%. More than half said that the quality of their care has decreased in line with cuts to funding.

EIP services are also losing staff, and having to reduce the number of treatments and support they can offer people. Even worse, some EIP services are being disbanded entirely or absorbed into community mental health teams.

The result is that after more than a decade of progress and success, EIP care is effectively disappearing in some areas of the country.

And while some services are managing to maintain strong outcomes despite reduced budgets, the overall picture is one of profound concern and uncertainty about the future for people experiencing psychosis. EIP services are at a tipping point, and further cuts will seriously threaten their capacity to support some of the most vulnerable young people in our society. We are at risk of losing a generation.

The Government has made a commitment to put mental health on a par with physical health in the NHS, but that is far from a reality as things stand. Ensuring that EIP services have the funding they need would be one obvious step towards achieving that.

The Government, the NHS and commissioners must make EIP services a priority at a national and local level. We are calling on them to act now, or risk writing off the future wellbeing of tens of thousands of young people across the country.

Professor Max Birchwood

Co-founder, IRIS Network
Professor of Youth Mental Health, University of Warwick

“After more than a decade of progress and success, EIP care is effectively disappearing in some areas of the country”

Psychosis and young people

Psychosis is a medical term used to describe hearing or seeing things that are not there, or holding delusional beliefs. Common examples include hearing voices or believing that people are trying to do you harm. It can be experienced as a one-off episode, but if left untreated can lead to long term illness and disability.

Around 1 in 100 people will develop a full psychotic episode in their lifetime. The vast majority (8 out of 10) will experience their first episode between the ages of 15 and 30.⁶

Psychosis can have an extremely damaging impact on a young person's wellbeing and quality of life. It can affect their relationships with friends and family, and their ability to engage in education, training and employment. It also makes it very difficult to manage everyday tasks, like paying bills or rent.

This leaves young people vulnerable to developing a serious mental health crisis, being detained in hospital under the Mental Health Act, or getting caught up in the criminal justice system.

Early intervention makes a massive difference in helping young people recover from a first episode of psychosis. When someone receives Early Intervention support within two months, their prospects of recovery are significantly improved, but a delay of longer than six months greatly reduces their chances.⁷

Similarly, when a young person receives Early Intervention support in the first 14 months of their illness, they are much more likely to make a full long term recovery.⁸



FACTS AND STATS A

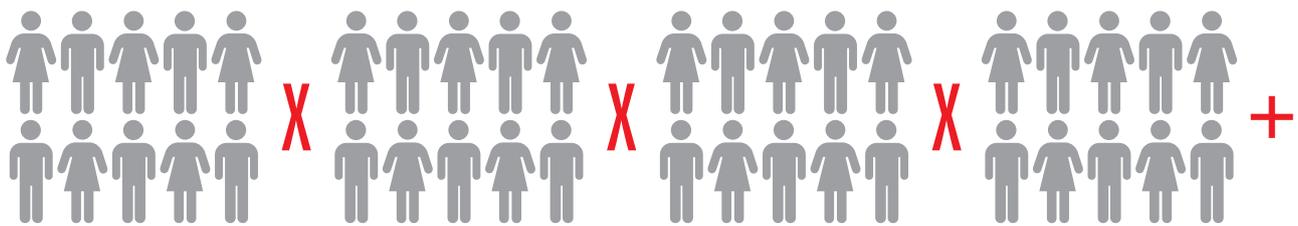
50% OF EIP SERVICES

have been **cut** in the past year



MORE THAN 10,000

young people get EIP care each year



35% OF PEOPLE

compared to

12% OF PEOPLE



under EIP care are in employment



in standard mental health care

ABOUT EIP SERVICES

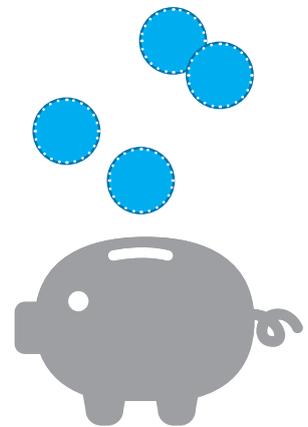
EIP support reduces the probability of someone being 'sectioned'

FROM 44%  TO 23% 

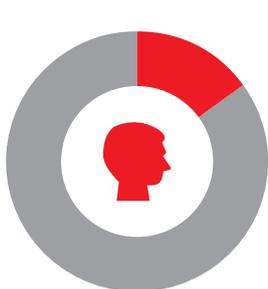
in the first two months of psychosis

If everyone who was eligible received early intervention, it would **save** the NHS

£44 MILLION EACH YEAR



EIP support **reduces the risk** of a young person taking their own life



FROM UP TO 15%
TO 1%



Why Early Intervention in Psychosis is so important

Early Intervention in Psychosis (EIP) teams are the best model for offering early intervention to young people with psychosis. They take a holistic approach to supporting people aged between 14 and 35 to recover from a first episode of psychosis. That includes offering support from a wide range of health professionals, including psychiatrists, psychologists, community mental health nurses, social workers and support workers.⁹ This gives young people a better chance of experiencing a good quality of life.



Interventions are most effective when provided by a specialist team. They often include family therapy, support with maintaining employment and education, advice on managing physical health care and help with developing support networks with family and friends. People normally receive EIP care for a minimum of three years, and a maximum of five years.

Evidence shows that EIP services help people recover and offer the NHS significant savings, in the following ways:

Reduced suicide and homicide rates

EIP support reduces the risk of a young person with psychosis taking their own life, from up to 15% (the risk of suicide for people with psychosis), to just 1%.¹⁰

The risk of someone with untreated psychosis committing homicide is very small (around 0.17%). However, early intervention reduces that to 0.011%.¹¹

Better physical health

Young people being treated for psychosis are vulnerable to developing side effects from antipsychotic medication, including rapid weight gain and changes to metabolism. Over time, these can lead to conditions like diabetes, heart disease and cancer, which puts young people at significant risk of dying 15-20 years younger than the general population.¹²

EIP teams offer young people support with managing their physical health which is rarely available to them from their GP or other mental health services. This is recognised in the international Healthy Active Lives (HeAL) consensus statement.¹³

Reducing demand on other services

People who have EIP support are less likely to need other mental health services, such as expensive hospital care, which results in significant savings for the NHS. It also reduces the probability of someone being detained in hospital under the Mental Health Act from 44% to 23% in the first two months of psychosis.¹⁴ NHS England has acknowledged that cuts to Early Intervention services are increasing demand for beds on mental health wards for young people.¹⁵

By reducing dependence on hospital beds, EIP care saves the NHS an estimated £5,536 per person in the first year of psychosis, and £15,862 during the first three years.¹⁶ If early intervention was available to everyone who could benefit from it, the NHS would save £44million each year through reduced use of hospital beds.¹⁷

Improved employment and education prospects

The employment rate for young people under EIP care is 35%, compared to just 12% for people in standard mental health care.¹⁸

This leads to increased annual earnings of £4,299 per person, compared to people using other mental health services.¹⁹ The estimated cost of lost employment is around £2,000 lower for each person under EIP care per year.²⁰

Better experiences of care

Young people using EIP services²¹ say that they have more positive experiences of EIP care than of other mental health services. Young people said EIP support helped them gain a positive sense of self-identity, and develop strong family relationships (which in turn means family members are more engaged in the care that a young person receives).

They also welcomed the flexibility of EIP support, especially in relation to the length of time that it is available to them.

Evidence from the front line

“I felt valued as a person”

Denny Reader (32), from Warwickshire, developed psychosis as a teenager. He says that the support he received from his Early Intervention service was crucial in helping him recover.

“I had been ill for two years, and was sectioned twice, before being referred to the Early Intervention team when I was 23. The staff were incredibly positive and respectful, and I felt really valued as a person.

It was much more of a holistic approach than previous support I’d received. They talked to me about my physical health, as well my mental health, and made sure I was looking after myself.

I was referred to a psychologist, who helped me to become more aware of my own condition. As I gained more insight into my illness, I felt I was more in control of it, which played a big part in helping me recover. I was also given a fantastic social worker, who really listened to me, and we struck up a very strong relationship. He helped me to get involved in social groups, including a bowling group, which enabled me to meet other people and feel less isolated.



I was also encouraged to volunteer in the café in my local mental health centre. Since then, I’ve also joined the board of trustees at the centre, which has given me a lot of pride and self-esteem.

Without early intervention, I would have become a lot more isolated and reclusive, and would have had less insight into my condition. Soon I am going to be discharged completely from mental health services, which shows how much of a difference early intervention made for me.”

“We offer people support that they would not otherwise get”

Paul* is an EIP service lead. He and his colleagues have fought hard to protect his service from cuts by demonstrating the strength of their outcomes.

“To protect our service from all the financial uncertainties we’re facing, we’re really proactive and positive about making the case for our service to senior management in our Trust.

We collect evidence on everything from patient satisfaction, to the number of people we’ve been able to discharge back into primary care because they no longer require our support – that’s currently around 75% of the people we work with.

We also offer additional services to our clients which they otherwise might not receive. For example, we have a strategy for supporting people with their physical health, including offering advice on healthy living, and taking blood samples.

It’s that willingness to take extra steps and to innovate that makes EIP services so attractive, and that’s what we’ve tried to shout about. I think we’re able to do that because the people who work for EIP services are really passionate and personally invested in what they do. We have a clear tangible goal of helping young people to recover, which perhaps isn’t the same for services that help chronically ill people.

We know we’ll have to continue to shout about how important our work is, if we’re going to be able to keep offering the level of support we currently do”.

Tackling inequality for mental health

The value and benefits of Early Intervention in Psychosis (EIP) services are even more important in the context of the Government's commitment to achieving 'parity of esteem' for mental health within the NHS. That means giving people with mental illness equal priority and quality of care to people with physical illness.

But this is far from a reality for people with psychosis. Many people miss out on crucial treatments recommended by the National Institute for Health and Care Excellence (NICE). As a result, people with psychosis often face appalling health problems and poor quality of life.

- People with psychosis and other severe mental illnesses die on average 15-20 years younger than the general population, mainly from preventable physical health problems.²²
- There are no mandatory waiting times for access to specialist mental health services, as there are in physical health care.²³
- Fewer than 30% of people with schizophrenia receive recommended physical health checks.²⁴
- Only 8% of people with psychosis and schizophrenia are in employment.²⁵
- Fewer than 50% of people with schizophrenia are offered recommended talking therapies.²⁶
- While NHS funding remains stable across the board, mental health trusts in England have had their funding cut by more than 2% in real terms over the past two years.²⁷

In the context of these health inequalities, the value of the holistic support offered by EIP services is even more clear. The support they offer in terms of physical health, talking therapies, and employment support, are rarely available to young people with psychosis anywhere else in the health system.

This was recognised by the Schizophrenia Commission in 2012, which recommended EIP services as one of the most effective models for supporting people with psychosis, and said that the holistic ethos of EIP services should underpin all mental health services for people affected by psychosis.²⁸

EIP services should be viewed by local and national decision-makers as a solution to some of the problems caused by inequalities in the NHS, and an important step towards achieving 'parity of esteem'.

“Early Intervention in Psychosis has been the most positive development in mental health services since the beginning of community care”

The Schizophrenia Commission 2012

Early intervention under threat

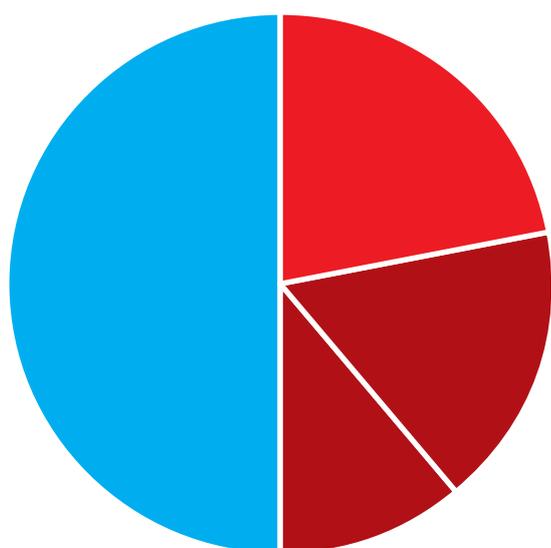
From December 2013 – January 2014, Rethink Mental Illness and the IRIS Network conducted a comprehensive survey of Early Intervention in Psychosis (EIP) services across England to investigate how economic and political pressures are impacting on them.²⁹ More than 75% of EIP services and teams completed the survey.

We asked:

- Compared with the last financial year, how has your overall service budget changed?
- How do you feel the above changes (and any other relevant factors) have affected the quality of the EIP service?
- Has the skill mix in your team changed? For example: new posts, increased staff training, downgrading of posts, loss of certain posts.

What we found

Budgets are being squeezed in half of all EIP services



50% of services say their budget has decreased in the past year.

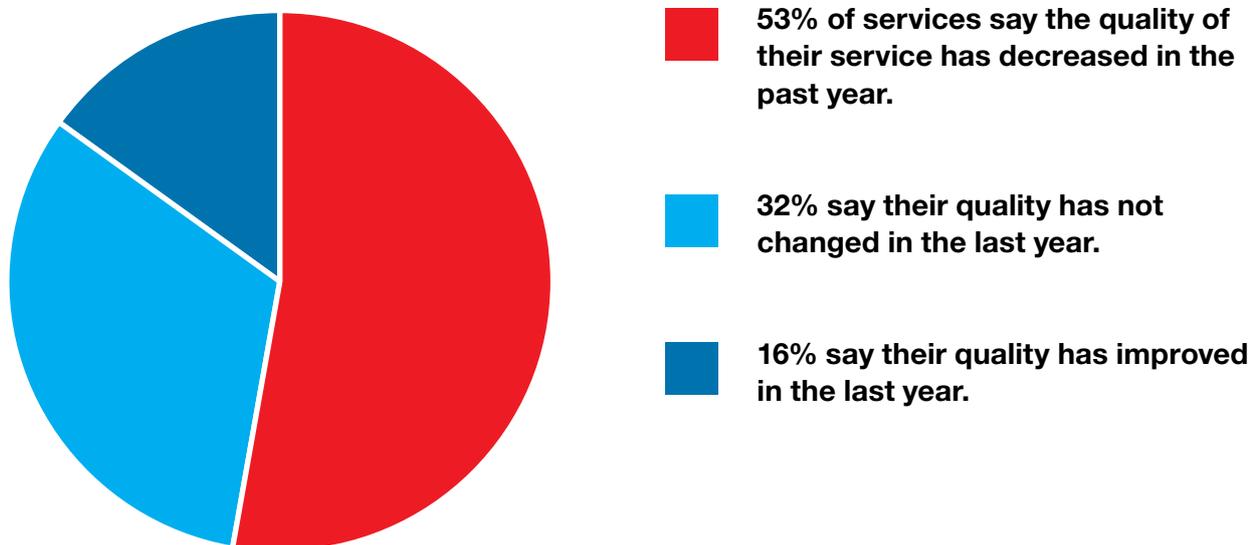
17% say their budget has been reduced by 6-10%.

11% say they have faced cuts of 11-20% in the last year.

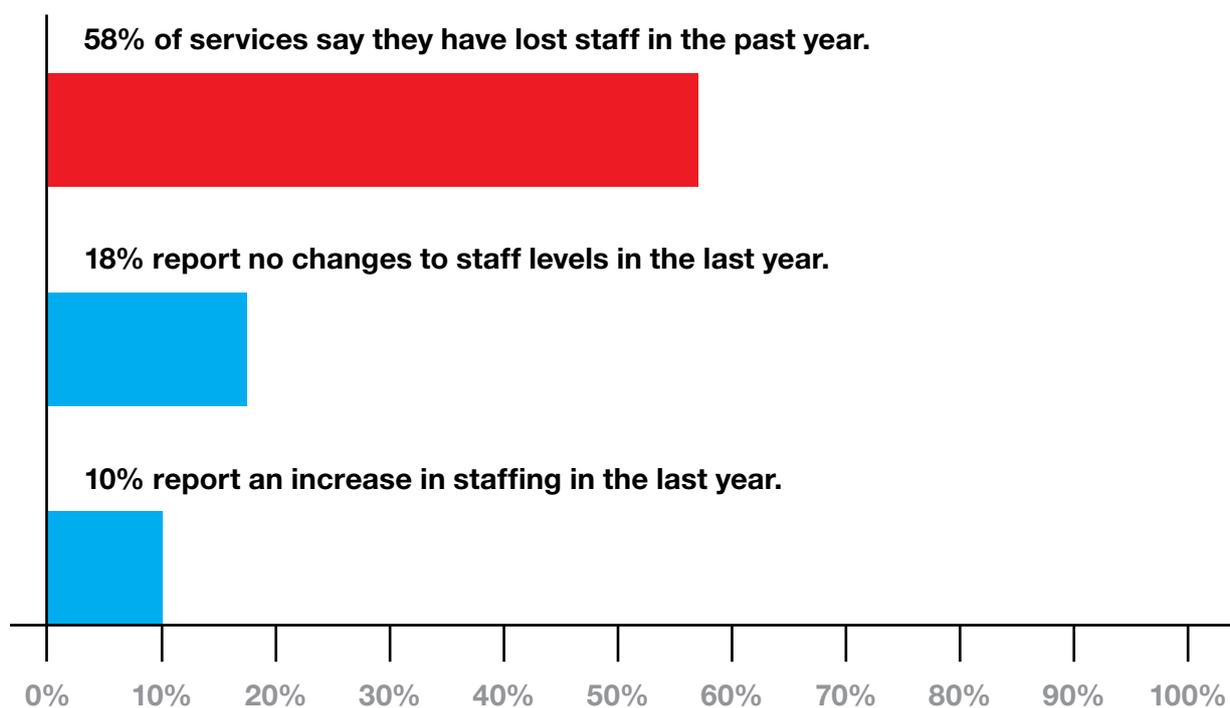
50% of services say their budget has not changed in the last year.

No services say that their budget has increased in the last year.

Quality of EIP services is being adversely affected



Staff posts are being lost or downgraded



What are the implications for EIP services, and the young people they support?

Loss of crucial specialist support and expertise

More than half of services say they have lost staff, or had to downgrade staff posts, while others report that the skills mix within the team has changed. In some cases services say they have lost specialist staff such as vocational support workers, or had to replace them with staff who lack expertise.

Other services were unable to replace vacant posts due to lack of funding. This means that young people are missing out on the unique, holistic support which makes EIP more effective in treating psychosis than other community mental health services.

Higher than recommended caseloads

Our survey did not explicitly ask about caseloads, but tellingly, nearly a third of teams (31%) report that their caseloads have risen above the recommended level. Services say this is due to staff losses, pressure to meet targets, and difficulties in discharging people to other mental health teams.

The result is that young people are getting less time and support from EIP professionals. It also means that EIP teams are forced to discharge young people to less effective mental health services or primary care, before they have completed the recommended three years of support.

Reduced range of interventions offered

One of the strengths of the EIP model is the range of interventions and services they offer to young people. Services report increasing concerns at having to reduce the available range of interventions due to staff losses and increasing time pressures. This means that young people with psychosis are less likely to get support with their physical health, employment and training, and social skills.

Services say that they have less scope to offer outreach support, such as working with local schools or primary services to increase awareness of psychosis and how it can be treated. Some services also say that they have had to reduce the family support they offer. This means that carers are less able to play an active role in the treatment that young people receive, and are given less information about their condition.

Uncertainty impacting on staff morale

A number of services raise concerns about wider changes taking place within their mental health trust. Some services have just been through reconfigurations, and are still unsure about how that could impact what they do on a long term basis. Other services are anxious about what the next round of commissioning decisions will bring in April 2014.

Generally, there is a great deal of uncertainty among services about the future, despite the excellent outcomes that EIP services achieve. This is starting to affect staff morale, which in turn impacts on the care given to young people with psychosis.

Delays in accessing EIP care

Higher caseloads and reduced levels of staff are resulting in many young people having to wait even longer to access services. This damages their prospects of recovering from a first episode of psychosis, and increases the likelihood that they will be hospitalised or detained under the Mental Health Act.

It also reduces their chances of making a successful long term recovery from mental illness, and being able to play a meaningful role in society.

Evidence from the front line

“Vulnerable young people are being left to fend for themselves”

John* is a community mental health nurse in the north east of England.

“We used to have a large, standalone EIP service in our area, made up of several teams and around 40 dedicated clinical staff.

But that all changed two years ago. Our Trust had to cut community mental health provision by over 10%, so it merged the EIP teams with the Community Mental Health Teams (CMHTs).

As a result, early intervention has effectively disappeared in our area. For a start, we now have much less capacity to identify and take on young people who could benefit from our support. We used to identify around 100 young people each year, but now that’s down to 50. It means that a lot of vulnerable young people are being left to fend for themselves.

Everyone has much bigger caseloads now. We each used to support around 15 people at a time at the EIP service, but now it can be anything up to 45 people. As a result, we can’t give young people the time or specialist support they really need.

One of the biggest losses has been the social and health support we used to offer, like getting people involved in running groups, going to the gym, social events and playing football. All that’s completely gone, because we just don’t have the time, resources or staff to keep it going.

It feels like we’re now back at the same place we were ten years ago, before the EIP service was first introduced. The staff from the EIP service have been left completely demoralised, and many have decided to leave. They no longer feel they can make a meaningful contribution to supporting young people with psychosis.”



* Not his real name.

Recommendations

This report shows that Early Intervention in Psychosis (EIP) services are struggling to maintain quality support for young people with psychosis, in the face of funding cuts and increasing uncertainty about the future.

EIP is not a luxury service, and further cuts to funding will leave tens of thousands of young people without the support they need to recover and gain a good quality of life. It will result in more young people going into crisis or being detained under the Mental Health Act, and will place NHS services under even greater strain. NHS England has acknowledged that cuts to Early Intervention services are increasing demand for beds on mental health wards for young people.³⁰

But despite the excellent clinical and economic outcomes that EIP services offer, they are currently overlooked in the NHS's quality indicator frameworks. This means that national and local decision-makers cannot be held to account for whether or not young people across the country are able to access EIP care. We think this is unacceptable, and we know what needs to be done.



Call to action

The human, social and economic costs of failing to protect Early Intervention services are too great to allow that to happen. Rethink Mental Illness and the IRIS Network are calling on the Government, NHS England and commissioners to ensure that young people with psychosis get the support they need by implementing the following recommendations:

- 1.** **Clinical Commissioning Groups (CCGs)** must commission EIP services that offer specialist employment and physical health support. They should ensure that services meet local demand, by using available data which predicts the prevalence of first episode psychosis in their area.³¹
- 2.** **The Government** must introduce a maximum waiting time of 28 days for accessing EIP services from the point of referral, ensuring that young people receive EIP care as early in their illness as possible.
- 3.** **NHS England** must design CQUINs and other financial incentives to ensure local commissioners prioritise and reward good quality EIP services.
- 4.** **The Government** must collect data about how long people wait before receiving EIP care, as part of the National Mental Health Minimum Data Set.³²
- 5.** **NHS England** should carry out an annual audit of EIP services to check how rates of access compare to overall demands, and to monitor delays in accessing care. It should also measure whether EIP services reflect best practice as outlined in the IRIS Network guidelines.³³
- 6.** **The Government** should include measures relating to EIP (such as speed of access to EIP care) in the various quality indicator frameworks for the NHS.
- 7.** **CCGs** should design local care pathways through consultation with young people with lived experience of psychosis, carers and families.
- 8.** **NHS England** should make it mandatory for mental health provider organisations to collect data on the amount of time people wait before receiving treatment for a first episode of psychosis, delays in accessing EIP and rates of access to services. This data should then be incorporated into the various outcomes frameworks.³⁴



Protecting young people: what politicians need to do now

This report shows that the reality for young people with psychosis contrasts starkly with what politicians say should be happening. The value and importance of early intervention for young people is recognised in a number of key strategies and policies. But they will have little or no impact unless national and local decision-makers take action to make them a reality.

- The Government's mental health strategy highlights the impressive clinical outcomes achieved by EIP services, and the long term economic savings they offer.³⁵
- The recently updated National Institute for Health and Care Excellence (NICE) guidelines on psychosis and schizophrenia recommend that anyone experiencing the onset of psychosis should be offered EIP care regardless of their age.³⁶
- The Government's recent mental health action plan notes that early intervention can make a "massive difference" in addressing mental health problems among young people.³⁷

In the current economic climate, it is more important than ever that health services maximise their resources and reduce costs, while improving people's care and creating lasting positive outcomes. At a national level, we are seeing a deliberate shift toward evidence-based policy and practice. That is why it is so baffling that services which have such impressive outcomes, and offer such significant savings, are facing major funding cuts.

National and local decision-makers need to recognise the severe, long term human and economic impact of allowing EIP services to be diluted or hollowed out. Not only does early intervention help people recover and offer savings, it saves lives.

There is only one way to avoid writing off a generation of young people with psychosis, and that is to secure the future of services that have been proven to work.

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**Leading the way to a better
quality of life for everyone
affected by severe mental illness.**

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