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Early Youth Engagement in first episode psychosis services: the EYE project

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Co-applicants and collaborators

Institute of Psychiatry

Sussex Partnership NHS Foundation Trust

University of Sussex, Psychology

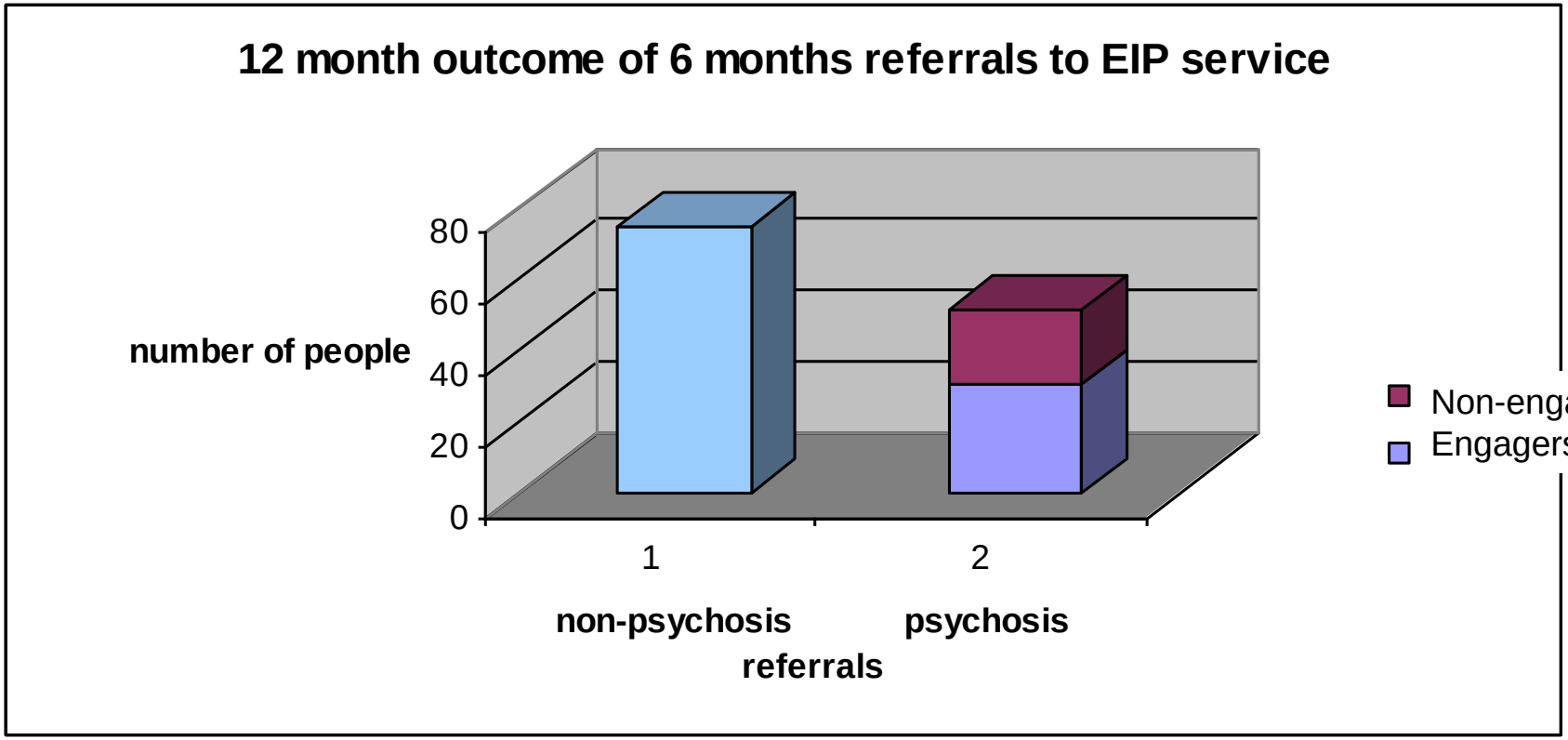
What's the problem with engagement?

- Psychosis affects 7500 young people per year
  - Distressing symptoms
  - Poor quality of life
  - 25 years reduction in life expectancy

- Early Intervention in Psychosis in critical period improves
  - Symptoms, function, course, outcome and suicide

- 25-30% of people disengage within 12 months
  - Linked to younger age, substance use, lack of knowledge

A similar pattern in Sussex?



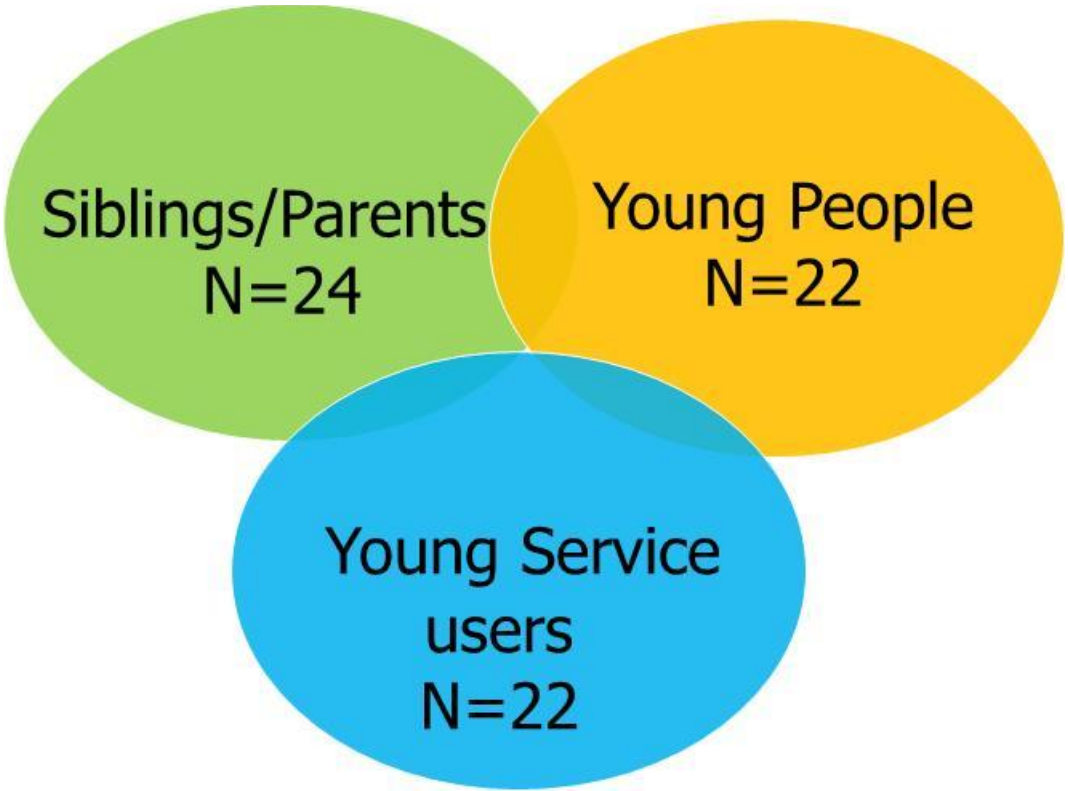
Research Questions & Aims

- Phase 1 - What are facilitators and barriers to engagement in EIP?
- Phase 2 - Translation of themes into a workable youth focussed service adaptation
- Phase 3 - Can youth-focussed service adaptations be effectively implemented to improve engagement in EIP services?

Phase 1 focus groups/interviews

Sussex, Surrey and Kent

N=68 people



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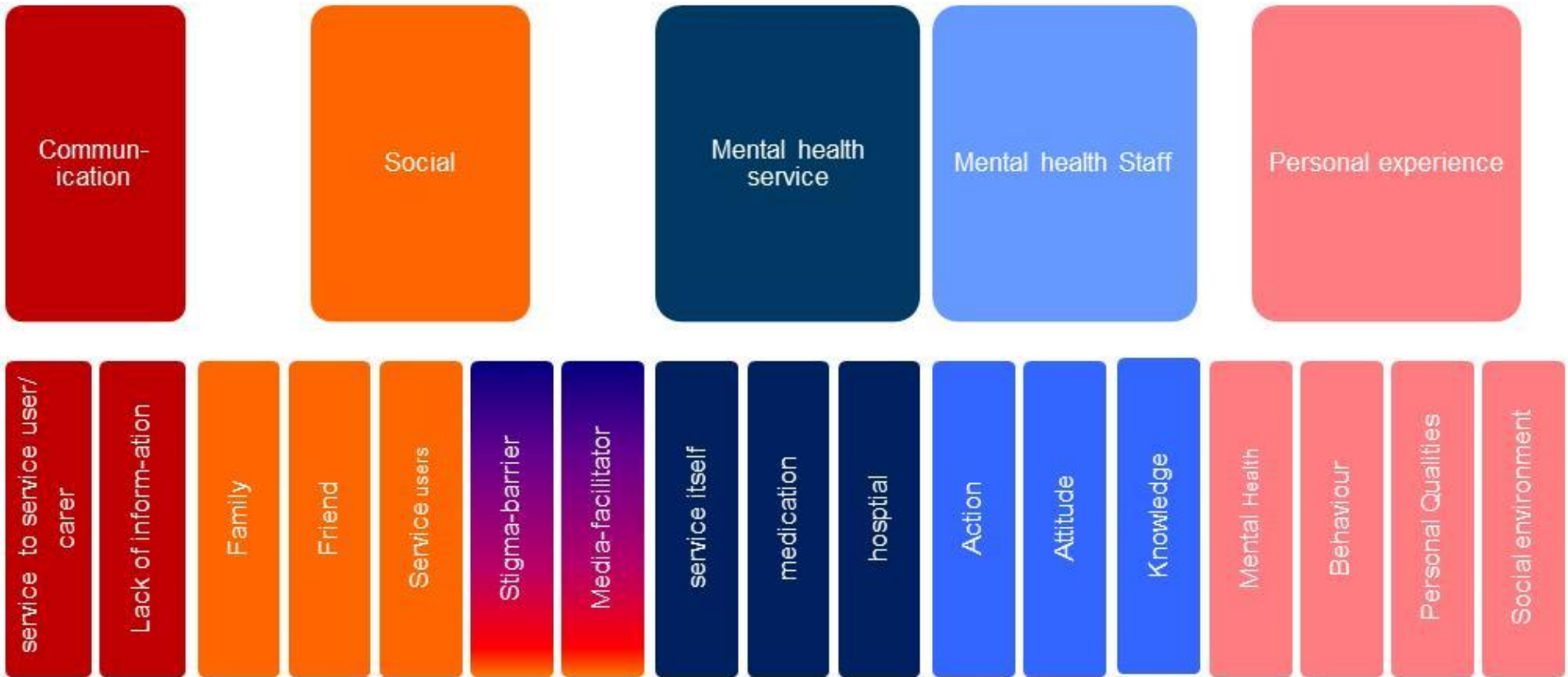
Phase 1 outcomes

Barrier and Facilitator themes



Phase 1 - Barriers

Information
"not knowing what will happen when I get help and what options I have…"

Social
"I said, look, I've got to shoot off at 11 o'clock, because I've got to be there at twelve. And they say, oh no, don't worry about it. You'll be alright. So I am riding around on the motorbike … and I get a phone call and its like one o'clock or something."

Mental health service
"Being labelled as mental and losing control of my own life in terms of reliance on drugs."

Phase 1 - Barriers

Mental health staff

"Well, I think part of ah the role of somebody who is a [clinician] they have to be quite easy going, quite calm, quite placid. And that can frustrate you a little bit if you're not in the right frame of mind. If somebody's speaking to you as if they've taken a load of Valium, umm, it can grate on you ever so slightly…'

Personal Barriers

'Yeah, I'm like it with everything, if I don't have a connection straight away… I just have to have a connection straight away otherwise I am just not interested.

Phase 1 -facilitators

Information
"Knowing that I am not alone and that there are millions of people that have the same illness and people can help and how they can help."

'Information and answers can help people get places quicker.

'I'd probably want to be reassured, we were quite scared that she would be taken away, that she would be sectioned …

Social
"I think they might have helped me to engage with the services because they reminded me that I had a place to get back to if you see what I mean like I've got a goal you know."

Mental health Service
'I dunno, do a plan, like to help me be better, not just say take this and you'll be better within that amount.

"they say it's a reuptake inhibitor, it does this, and its scientifically proven, but there are, you know, it's also proven by experiments that you know human touch releases Oxytocin, exercise releases endorphins"

Phase 1 -facilitators

Mental health staff

'Um, when I meet with the um, [clinician], um, what I do like is that he doesn't just look at my medication, he looks at the whole bigger, like big picture. So he'll discuss what else is going on in my life, um, talks about education and stuff like that, you know, anything that could be happening in my life at the moment, or in the near future and, I think that's, I think that's a good thing, because obviously I do need the medication but, my diagnosis can get in the way of sort of my personal life and, you know my social life, that sort of thing'

Personal Qualities

'I just knew, you know, I just knew. I knew what would help. I knew what wouldn't help. Partly through experience, from, you know, in the past, things that hadn't worked, um, yeah, yeah.'

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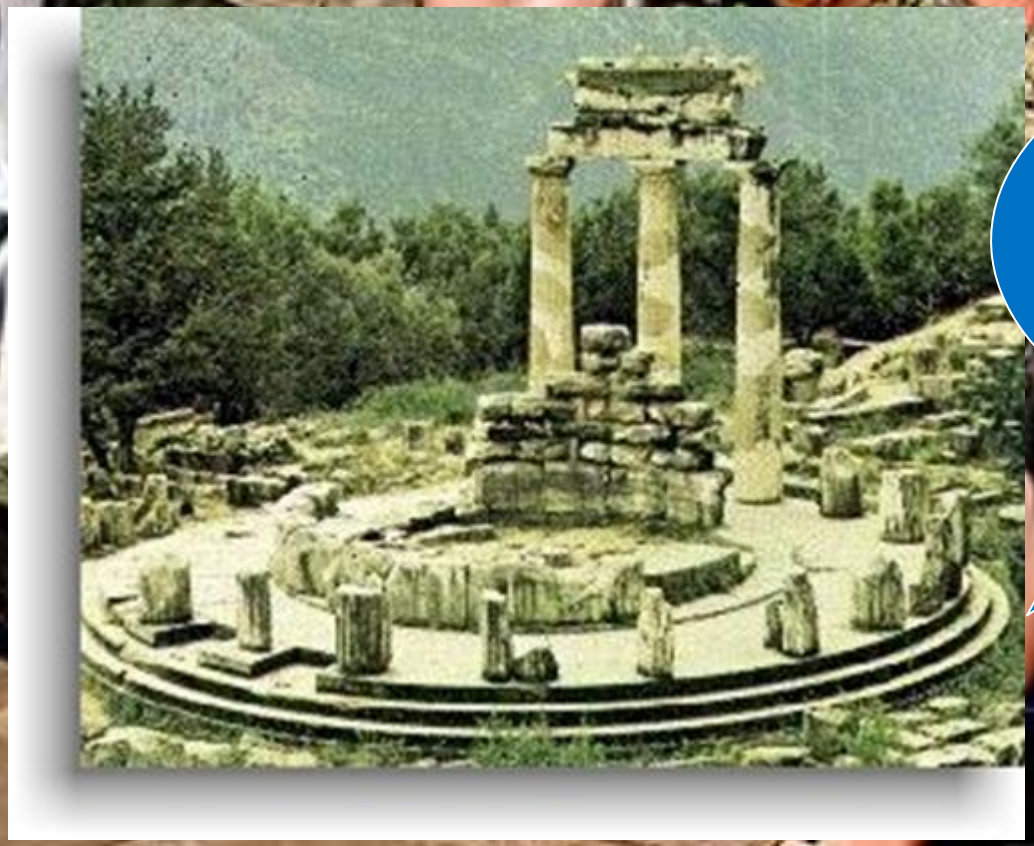
Phase 2 – Delphi Consultation

& Implementation Science (Tansella and Thornicroft 2009)



National EIP leads,
Clinical directors, Service managers
Team leaders, Care co-ordinators
Psychiatrists, Psychologists, Pharmacists, Culture carriers
N=20, 22, 14

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Information

Myth busting booklets
Treatment choice booklets
Website
Help seeking tool
Carers/schools pack
Improved GP links

Social

Family and friends protocol
Peer workers

Mental Health Service

Parallel family and service user social support group

Mental Health staff

Transparent, flexible
Goal-focussed engagement
Using MI principles and considering lifecycles
Service user/carer led training

Personal qualities

Information booklets
Website and blog
Help seeking tool

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Recovery

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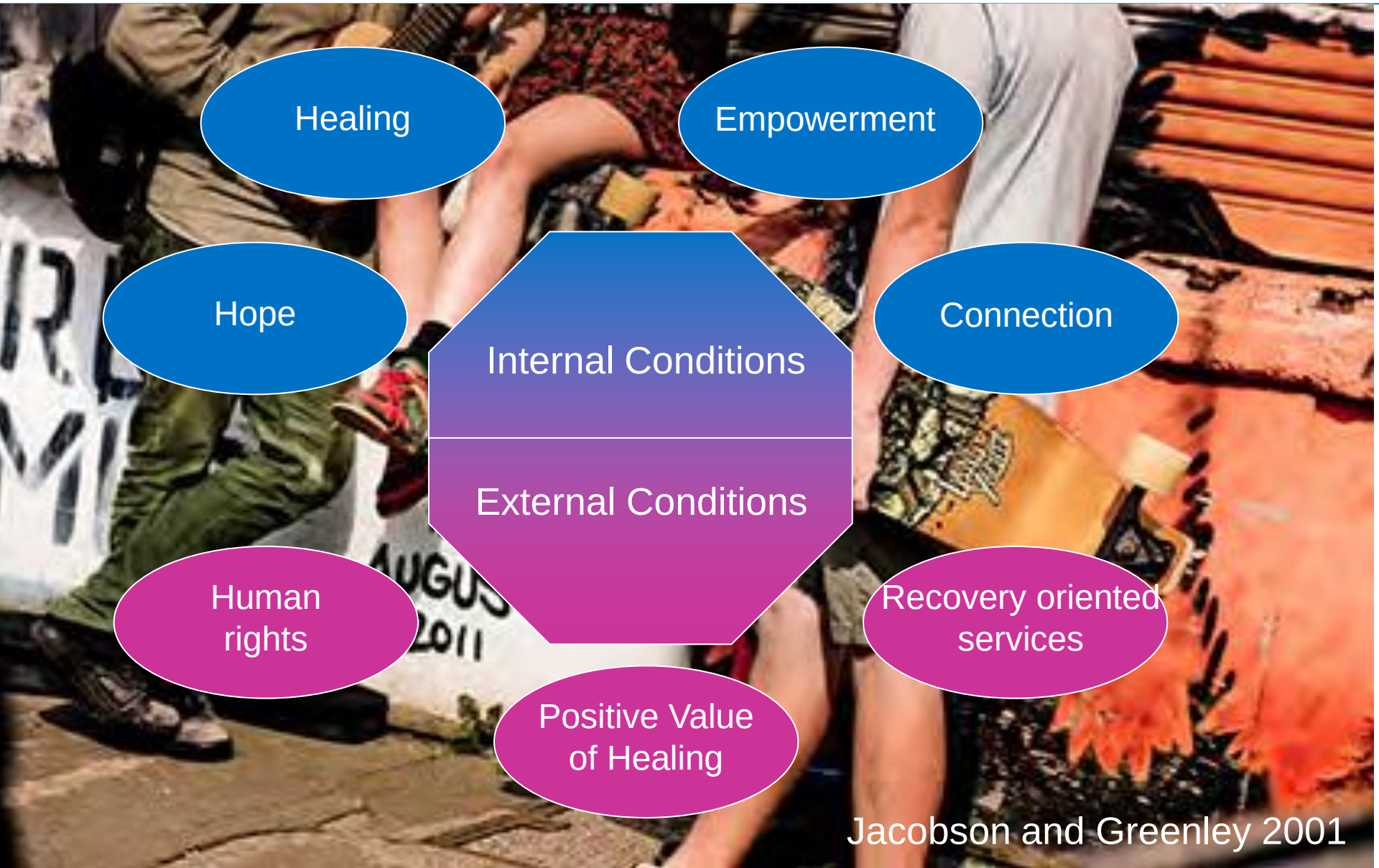

Jacobson and Greenley 2001

Home

eye.sussexpartnershipstaging.org.uk

Is anyone else like me?

The EYE Project: Engaging Young people Early in mental health and wellbeing for psychosis

Are you a young person who is worried that there's something wrong with you? Have you already been referred to or seen someone from a mental health service? Or an early intervention in psychosis service? Want some advice or answers? Then this website is for you. It has been produced with and for young people.

Why bother with this website?

This website doesn't make any assumptions about your experiences, where they've come from or what's caused them. Everyone's experiences are different. This website aims to tell you more about some common mental health problems and about mental health services, what they can offer, how they might help and how you might benefit.

> I think knowing that other young people have it as well, really helps, because a lot of people think 'oh I'm really unusual' and kind of shy away from it. But I think when you do realise how many other people can have the same problem it helps. Get on line, get educated and then if you think you need it.. get help' - Kai aged 16

Young people have mental illnesses too! Did you know that 1 out of every 10 teenagers will have some sort of early mental health problem and as many as 2-3 people out of 100 will develop psychosis? Imagine nearly a third of a college class having one problem or another. This is normal!

Who is this site for and how can it help?

Your stories:

Carl's story

"Being open is

Family and friends:

- Advice for friends

Get involved:

Visit or post on our blog

GET HELP NOW

HIDE PAGE

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Is anyone else like me?

The EYE Project: Engaging Young people Early in mental health and wellbeing for psychosis

Carers

- What is psychosis?
- Warning signs
- Why avoiding anxiety doesn't help
- Who's to blame?
- How you can help
- Challenges you may face
- Looking after yourself
- What to expect from an EIP service?
- Family and friends stories
  - Family and friends story one
  - Family and friends story two
- Your family or friend story
  - Share your family & friends story
- Information pack for schools

How to help your friend or family member

Below are some suggestions for things that might be helpful for you to do, or not do, to help your friend or relative to get better. When people experience psychosis, they often go first through a psychosis phase and then through a recovery phase (see the section on what is psychosis). Listening and trying to understand is especially important when someone is experiencing psychosis, and promoting independence is more important when someone is recovering, but other things like keeping calm and taking time out for yourself are important all the time.

Do:

Listen and try to understand what your friend or relative is trying to tell you. This may be hard as they may be telling you some things that sound quite unusual, unbelievable or distressing BUT the more you listen the more you will understand and also for your relative or friend having someone who they can talk to will help them to make sense of what's going on and may even make them start to question it.

Encourage your friend or relative to get back to the things that they have previously enjoyed in life, or to take up new hobbies, social activities, college courses or job opportunities. You might remind them of their skills and strengths, and the things they're good at, but then let them decide how much they are able to do and how quickly. Tell them how well they're doing when they make even small steps to recovery. This will encourage them to keep going.

Think positively and be optimistic about the things that your friend or relative might want to do in life. Help them to think about the future and the things that they may want to get back to. Psychosis often begins when people are young so it's easy for it to interrupt college, university, work and friendship groups. Low mood, lack of energy and negative thinking about psychosis (self-stigma) can make it harder to get back to these things, but the more hopeful you are for your friend or family member, the more you think with them about their goals and how to get there, the more likely they will achieve things, in their own time.

GET HELP NOW
HIDE PAGE

Drugs and alcohol

eye.sussexpartnershipstaging.org.uk/drugs

Is anyone else like me?

The EYE Project: Engaging Young people Early in mental health and wellbeing for psychosis

Drugs and alcohol

- How can you tell if you've got a drug or alcohol problem?
- Telling the difference between drugs and mental illness
- Using drugs and alcohol for coping
- Where to go if you think you have a problem with drugs and alcohol

We will shortly be adding information on drugs and mental health. In the meantime, there's lots of really useful information on the talk to frank and RU-OK websites below.

http://www.talktofrank.com/

http://www.areyouok.org.uk/

Confidential Promise
Find out why you can trust us

Cover Your Tracks
Find out how to keep your visits private

The EYE Project is a service provided by:

Sussex Partnership NHS Foundation Trust, Swandean, Arundel Road, Worthing, West Sussex, BN13 3EP

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GET HELP NOW

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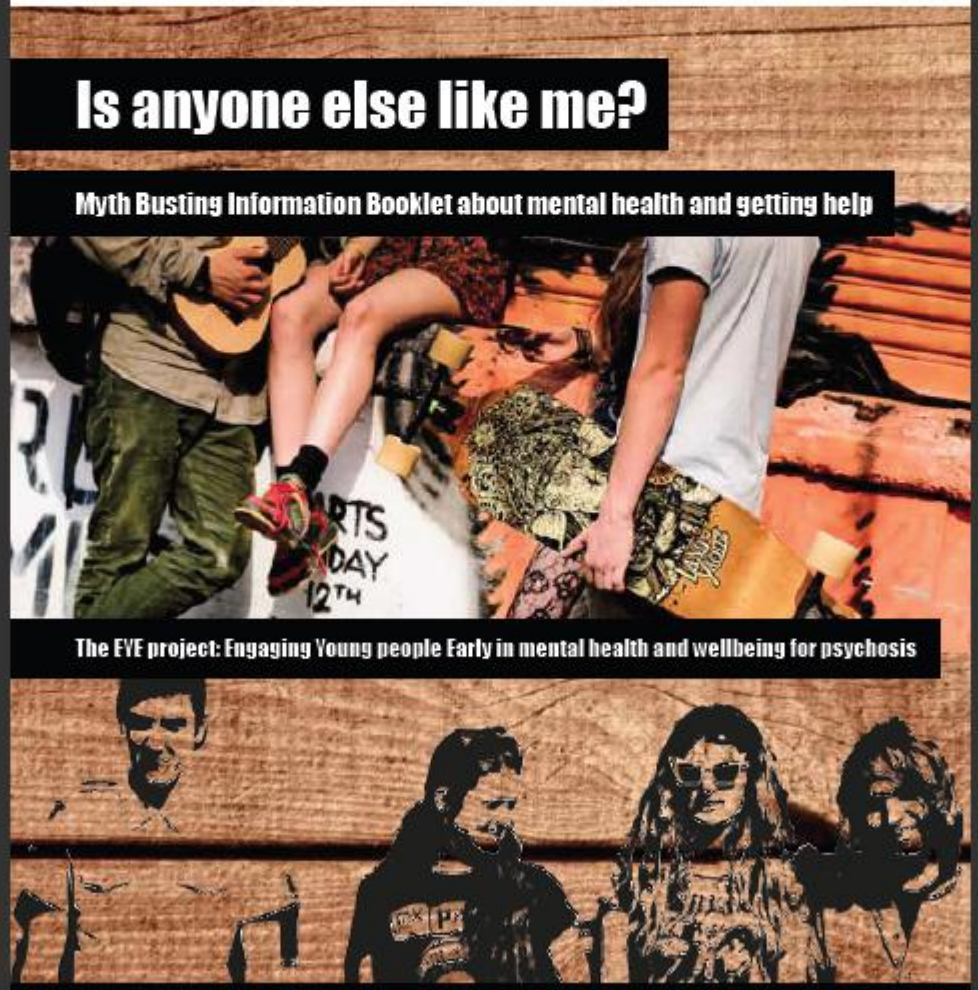
The EYE Project

Supporting Young Peoples Wellbeing and Mental Health



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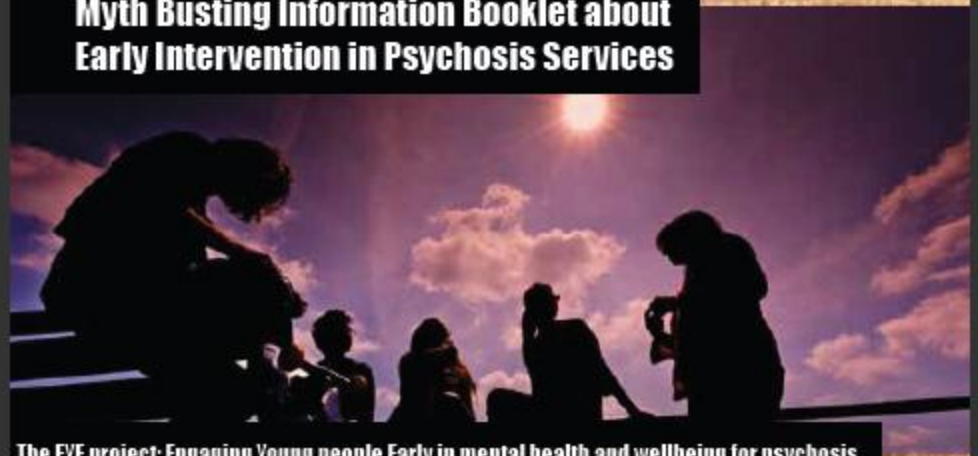
The EYE Project

Supporting Young Peoples Wellbeing and Mental Health

Is anyone else like me?

Myth Busting Information Booklet about Early Intervention in Psychosis Services



The EYE project: Engaging Young people Early in mental health and wellbeing for psychosis

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Young people have mental illnesses too!

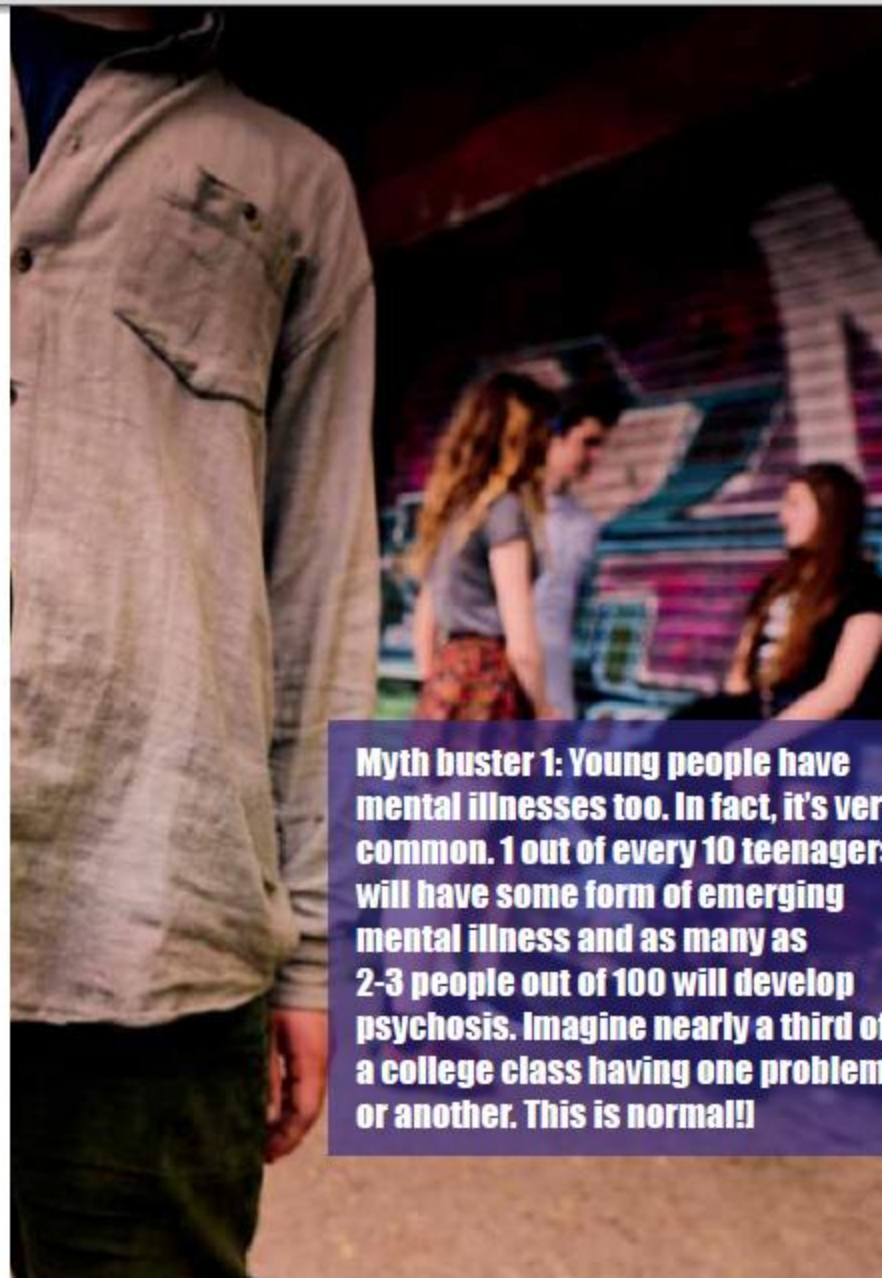
"I think knowing that other young people have it as well, really helps, because a lot of people think 'oh I'm really unusual' and kind of shy away from it. But I think when you do realise how many other people can have the same problem it helps."

Cassie aged 19

"I was hearing voices. I thought there was someone trying to get me out of the house. I thought I heard my neighbours walking past and I thought they were talking about me. Then they went round the corner and I could still hear them. I looked out and I thought I saw some guy in like a van trying to contact me and I thought well that's my next door neighbour or whatever cos I've seen him going in the house once.

"At first I thought it was my brother actually, and his girlfriend round there trying to get me out of the house, and then when the people knocked at the door, I went outside, just to check, and like a leaf fell from the tree and I thought I heard the leaf like saying something or something and then I knocked on this van and then I heard them say, 'oh she knows we're in here."

Ben aged 20



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What are EIP services? - 'It's what you do next that counts'

EIP stands for Early Intervention in Psychosis.

You might think the word psychosis is a bit unsettling and maybe it's putting you off reading anymore? Unfortunately, this may well be because of stigma! We can blame some of that on the media but we can feed into it too. What do you imagine when you think of psychosis? Would you be surprised to know that half of the people pictured in this booklet have psychosis?

Psychosis is not a diagnosis, it's just a description of a set of experiences. They include things like being paranoid, thinking someone's following you or out to get you, having other strange or upsetting thoughts or indeed real experience of hearing, seeing, feeling, smelling, and tasting things that other people don't. It can be scary at the time, but you can get over it, have a life, a good job, a relationship and a family. Even psychosis is quite common. Some people think that psychosis is just an extension of anxieties that we all have.

Different people respond to it differently though and some people struggle more and have a harder time and more long term problems. It's what you do next that counts!

If you think you have psychosis, or someone has suggested this to you, choosing to work with early intervention services is a first step to doing the best you can for yourself. EIP services try to meet and support young people with psychosis as quickly as possible so that they have the best and fastest recovery that they can. Your decisions are important here and they matter.

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Common myths

‘They put everyone on medicines’

Mythbuster 2 -Early intervention services don’t want to put everyone on medicines

Certainly one of the main treatments for psychosis is medication, BUT over half the people who are seen in EIP services DON’T end up having psychosis.

If you don’t have psychosis, you might just have a few meetings to reassure you, or you might be recommended to a different service that will suit you better. If you do have some of the unusual distressing experiences we’ve been talking about (psychosis), remember it’s quite common, and doesn’t mean you’re ‘weird’!

Someone will probably talk to you about medication because some people do find it really helpful to deal with stuff that’s happening and to stop it coming back again! After all, we take painkillers for headaches, coffee to wake up - so what’s the difference? Generally speaking you don’t absolutely have to take medication, and someone will also talk to you about other things that might help, like talking therapies, support for getting back to school, college or work, help with money and housing, and help with diet and exercise.

Our ‘Informed Choice in Treatments’ booklet tells you more about all sorts of things that might be helpful.

‘They put you in hospital’

Myth buster 3 - Early Intervention Services for Psychosis definitely DON’T want to put you in hospital!

EIP services definitely don’t want to put you in hospital
In fact, EIP services were specially set up to do the opposit

They try to make sure that things never get that difficult. They try to help you recognise ups and downs so that you can deal with issues early. Only if things are impossible to manage, very distressing and you or the EIP team really think things are unsafe will you end up going to hospital… and that doesn’t happen often because it also costs the NHS lots of money (e.g. about £2500 per week in 2013)! If you do end up going into hospital, there’s a booklet to help you with that too. Its called ‘Dealing with hospital: getting on with life’ .

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How to get help

Young people are most likely to have unusual and distressing experiences in their late teens or early 20's so EIP services work closely with schools, colleges, universities, GP surgeries, drug and alcohol services and other local young people's health and mental health services, so you can get help from any of these.

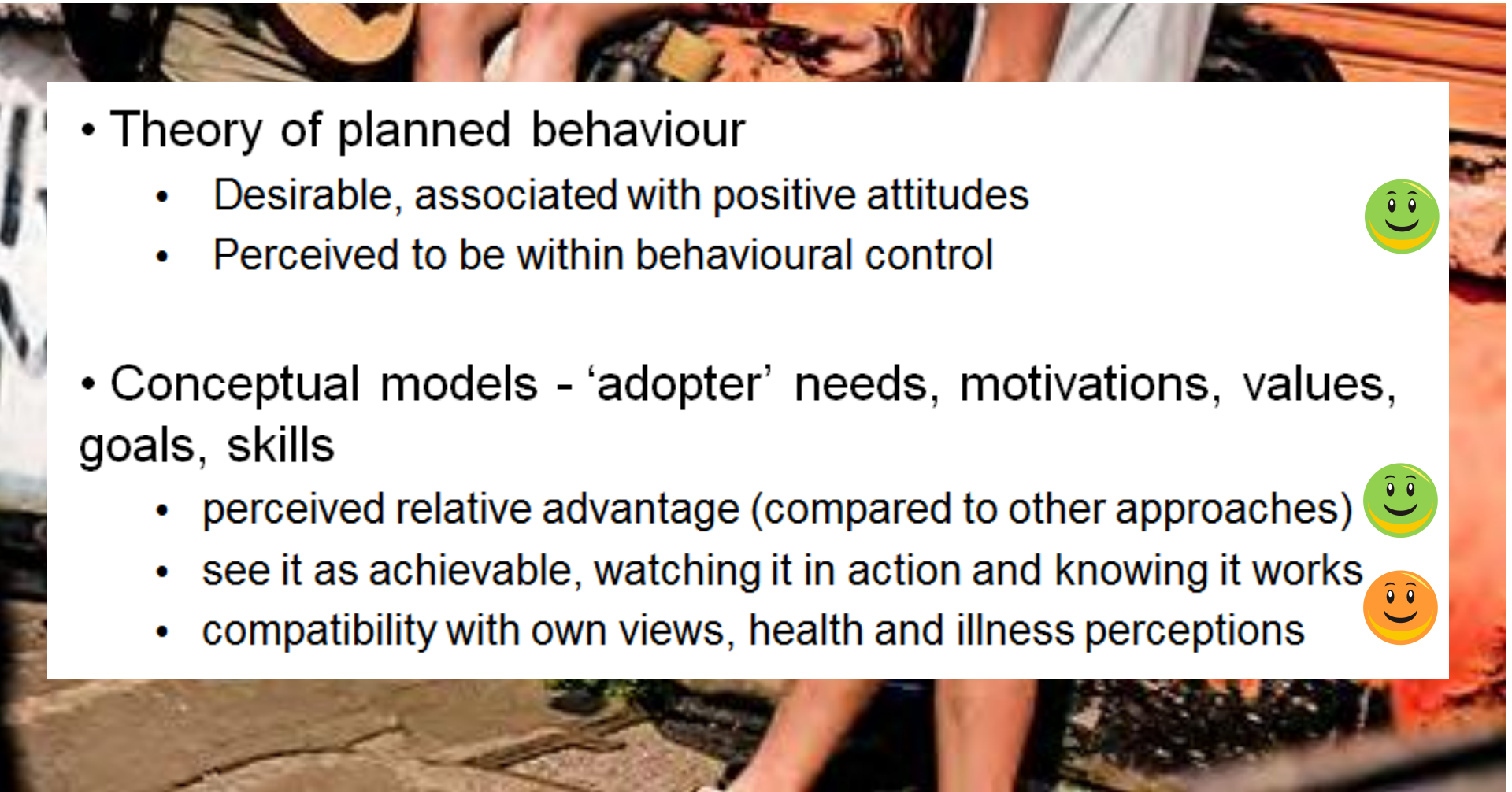
If you or the person you talk to think you may be having some unusual distressing experience like psychosis: talk to someone, they can contact a local EIP services. There are EIP services all over the country, aiming to meet you as quickly as possible, often within a few days, to try to help. You can even phone a service up yourself and talk to someone if you want to!

What happens when the service ends

EIP services normally offer a service for 2-3 years. This doesn't mean your problems are really severe, it's just what's offered to everyone. Research says that young people do best after these experiences if they get support for this long. You can use EIP services during this time to help get any part of your life where you want it to be.

At the end of 2-3 years, most young people don't need support from anyone and just carry on with their life. This is what the EIP service aims for as it tries to make sure people feel independent and confident. At the end of 2-3 years, some people do need a bit more on-going support either from their GP or from adult mental health services. The EIP service can help you to decide what's going to be the best thing for you.

Phase 2 -Facilitating implementation



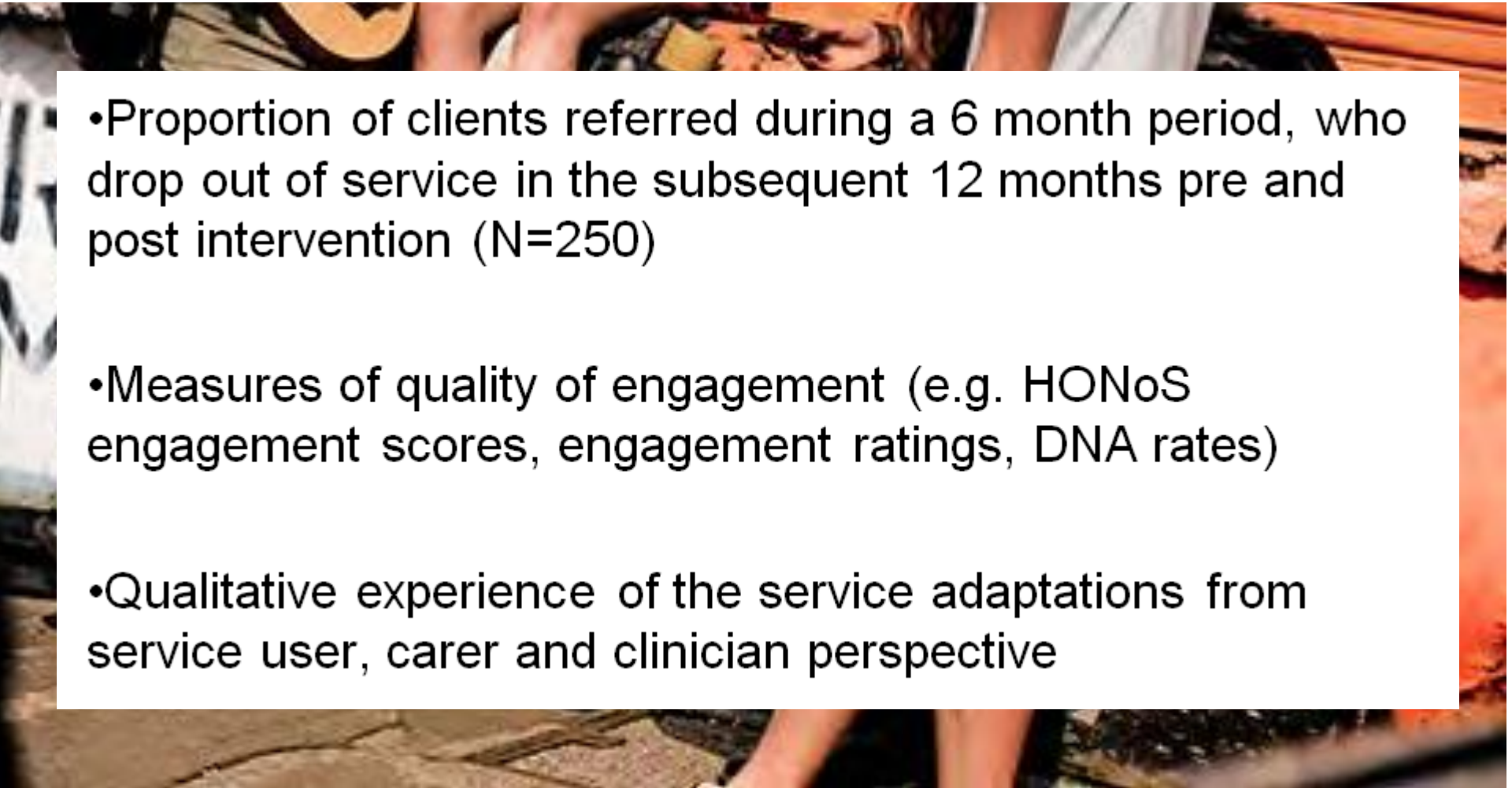
- Theory of planned behaviour
  - Desirable, associated with positive attitudes
  - Perceived to be within behavioural control

- Conceptual models - 'adopter' needs, motivations, values, goals, skills
  - perceived relative advantage (compared to other approaches)
  - see it as achievable, watching it in action and knowing it works
  - compatibility with own views, health and illness perceptions

Information, social integration, service choice, flexible goal focussed relationships

Leading to hope (agency and pathways to meet goals) & recovery

Phase 3 – outcome evaluation



- Proportion of clients referred during a 6 month period, who drop out of service in the subsequent 12 months pre and post intervention (N=250)

- Measures of quality of engagement (e.g. HONoS engagement scores, engagement ratings, DNA rates)

- Qualitative experience of the service adaptations from service user, carer and clinician perspective

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Thank you

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