

A photograph of three people laughing together outdoors. On the left, a woman with short blonde hair is laughing with her mouth open. In the center, a man with dark hair is laughing. On the right, a woman with blonde hair and glasses is laughing. They are sitting in front of a dark green metal trellis structure with plants. The background is slightly blurred, showing more of the trellis and some foliage.

rethink

severe mental illness

# Future Perfect

Mental health service users set out a vision for the 21st century

November 2005

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## Acknowledgements

We would like to acknowledge the contribution to this debate from the service users and carers who took part in the focus groups, without whom we could not have written this report. We would also like to extend many thanks to the Rethink service managers and staff who helped to co-ordinate the focus groups. Thanks go to Rachel Whale for facilitating focus groups and initial analysis of the results and to Jennifer Rankin, from the Institute for Public Policy Research (ippr), for focus groups facilitation and completing the final report for the Mental Health First programme: 'Mental Health in the Mainstream'. The Mental Health First programme is supported by Lilly and donations from members of Rethink and its supporters.

Written by Alison Faulkner & Kerry Williams



# 1. Introduction

*It is 2025 and a new government has recently been voted into office. As usual, health was at the top of the electorate's priorities and the election was dominated by claims and counter-claims about which party could best improve the health and wellbeing of the nation... Mental health is no longer regarded as the special concern of the health service or as a subject which is only relevant to a minority. Instead it is an issue that is everybody's business... Rankin (ippr, 2005)*

What might mental health services look like in ten, twenty or thirty years? Ask people who are closely connected with existing services, whether from a service user, carer or provider perspective, and you will probably receive a sceptical, if not a cynical, reply. It is hard for us not to root our responses in our experience of existing services. We have seen changes come and go over the decades and still some major elements of the service and the experience remain the same. Despite the major change that did take place during the second half of the 20th century - closure of the large institutions - there is still huge investment in inpatient beds. There is still stigma surrounding a mental illness diagnosis, social exclusion for those affected by it, and people still have difficulty in accessing appropriate services when they need them. There is a predominance of drug-orientated medical treatments, and a lack of alternative treatments available, in particular access to psychological therapies.

Making significant change to mental health services seems akin to trying to turn around a tanker: it is slow and cumbersome and highly unresponsive. Our view of the future is constrained by the tanker; it is hard to look as far as the horizon. Perhaps we are all ambivalent in our attitude towards change: we seek change or complain about the status quo, and yet we cling to that which is familiar. 'A change is as good as a rest' but 'the leopard does not change his spots'. We choose to go on holiday or move house, yet these are significant sources of stress for us in the hierarchy of stressful life events. We seek out people who are 'like us' with whom to live and to socialise. We like the safety of familiarity and we have difficulty envisaging a future that is much different from the past or the present.

But mental health services need to raise their eyes to the horizon in order to conceive of a vision relevant to our lives in the 21st Century. This is the challenge. In 2004, as part of our Mental Health First programme, Rethink joined forces with ippr (the Institute for Public Policy Research) to explore some of this ground: to clarify our present position and to create a vision for the future. A series of reports were published as a result of this work culminating in *Mental Health in the Mainstream* (Rankin, 2005).

In the Spring of 2005 Rethink carried out a series of focus groups with service users and carers as one contribution to the programme (see Appendix). A policy perspective is important, but so too are the views of service users and carers. In an attempt to circumvent potential scepticism, and to invite creative responses, we put a challenging scenario to the service users and carers we approached: What might the future look like without psychiatric hospitals? In addition we asked two supplementary questions in order to widen the discussion to include issues at the heart of successful social inclusion and quality of life for both service users and carers: How might services better support people into employment? and What would support a better quality of life for carers? This report presents our findings with the aim of informing and stimulating debate about the future of mental health care.

As one service user we spoke to said, when presented with a vision of a future of holistic and personal care:

**It's a dream, isn't it? It's not reality. It's a dream, it is not what's happening now and unfortunately we can't live in a dream world, we've got to live today. This is fantastic if it was real but it's not, it's just a dream, isn't it? We've got to live it, it's the here and now we've got to worry about, not there."**

Service user

Rethink runs Focusline, a telephone helpline service which offers confidential support, information and emotional support to the area of Nottingham, Leicestershire and South Derbyshire. Focusline is one of 13 helpline services run by Rethink. This service is available to any adult who has a mental health problem, carers and professional agencies.

Lincslines is a Rethink crisis accommodation and helpline service covering north and north-east Lincolnshire. It has a dedicated community mental health team link workers in place to liaise with Lincslines staff. Service users describe it as a service for the continuity of care out of hours.

Do Helplines Help?, a Rethink research report commissioned by the Department of Health, found that

- helplines could play an active role in the prevention of self-harm and suicide and case study examples of positive effects on care pathways were given
- helplines have a valuable role to play in the package of care available to service users, particularly in accessing out of hours support.

Rethink's self-management project has been running since 2001, producing a range of reports and materials. One service user says: "Self-management entails both a positive mental attitude and positive actions that help you get on with living your life the way you want to. [It] includes knowing when to recognise the illness limitations and adjusting your way of life to accommodate them and living your life to the full. The more you live your life and achieve goals, no matter how big or small, that is active self-management."

To find out more about Rethink services, our research and our self-management project, contact: 0845 456 0455. Email: [info@rethink.org](mailto:info@rethink.org) or visit: [www.rethink.org](http://www.rethink.org)

Getting involved: If you would like to support Rethink's work, why not become a regular donor? For more information, write to: Rethink, FREEPOST SEA 6772, Kingston Upon Thames, Surrey, KT1 1BR or telephone: 0845 456 0455. You can also donate online at: [www.rethink.org](http://www.rethink.org)

## 2. What might the future look like without psychiatric hospitals?

The first national survey of acute inpatient mental health wards was published in May 2005 (Sainsbury Centre for Mental Health). It found consistent understaffing with an over-reliance on bank and agency staff, a lack of therapeutic activities, and increasingly high levels of need amongst inpatients. These findings replicated those of several previous studies, both national and local. In September 2004, Mind reported the results of their Ward Watch campaign. They found that 51 per cent of recent or current inpatients reported being verbally or physically threatened during their stay, with 20 per cent reporting physical assault, and 18 per cent sexual harassment. In 1998, the Sainsbury Centre reported that inpatient care was unpopular, wards lacked basic amenities, many patients felt unsafe and many did not have their own rooms or private areas. Rethink's report 'Just one per cent' (Corry and Pinfold, 2003) found that people's worst experiences of engagement with mental health services centred on in-patient care.

This kind of data has long been backed up by personal accounts of the experience of being in hospital whether on a voluntary or compulsory basis (for example, Faulkner 2004; Rose, 2000). People describe incidents of poor or abusive treatment at the hands of mental health staff, a lack of basic amenities, privacy and information, and practices that can only be described as oppressive (e.g. observations). What, then, might the alternatives look like in our mental health services of the future?

### A Place of Safety

Faced with the scenario of a world without inpatient beds, most of the service users and carers who participated in our groups preferred to talk about retaining a place away from home, somewhere that would provide sanctuary or asylum. Several carers felt alarmed by the prospect of losing hospital wards, convinced of the need for a secure place for service users during a crisis, despite at times finding them deeply unhelpful places.

**"...I mean, when the crisis hits you're grateful for [inpatient wards] for the first few days, and then you spend the rest of the time trying to get them out of the wards because, you see, they achieve nothing..."**

**"We still need a secure place."** Service user

The majority of people appealed for small, purpose built crisis houses where people could be admitted for short periods purely to stabilise and manage the crisis episode helped by the necessary treatment interventions, a place where service users could be helped to recover from a crisis episode. People talked of a therapeutic environment with open spaces and gardens, complementary therapies available, and private rooms with ensuite facilities.

...a special house with special facilities...  
they can play basketball, a place they can do things.

**...something with nice grounds... animals**

... well they could have a premises where they are supported as much as they need. And they would also have to probably be on extremely good medication to start with, but like everybody else is saying, I can't imagine we don't need some place of refuge, an asylum somewhere...

The service offered would be person-centred and holistic, with the provision of therapeutic and recreational activities and one-to-one time with staff, as well as appropriate information and advice. Stays would be short to avoid institutionalisation and people would receive care appropriate to their level of distress and their stage of recovery. A significant part of the environment was improved contact with staff:

**“[you should] have that person as your personal person, mentor or whatever, so you can just go to them straight away and tell them of your fears, hopes, aspirations, whatever, rather than having to look for a nurse to talk to or somebody that’s not busy all the hours.”** Service user

### Prevention is better than cure

Many service users and carers expressed a strong belief that it should be possible in the future (and now) to prevent a crisis occurring in the first place, through access to the right services at the right time. Support would be available and accessible in the community round the clock, and this would include a range of services such as drop-ins or resource centres, befriending, and counselling. People who need help should be able to access services regardless of whether or not they are in the Care Programme Approach system. We are far from achieving this today. The Healthcare Commission recently reported (2005) that fewer than half of people using mental health services (on a Care Programme Approach) had access to crisis care, and only two-thirds of crisis resolution teams are operating 24 hours a day.

**“Well I’m honestly still a great believer that prevention is better, if you can prevent as soon as possible, that’s the best cure. And financially it’s the best way to keep us out of hospital but people don’t seem to realise that”** Service user

In the future, cultural barriers would be broken down to enable people from minority ethnic groups to access mainstream mental health services. In one group, carers talked about the importance of education and awareness, and of beginning this early in schools, in order that people would be able to recognise and prevent the early symptoms of psychosis.

**“Make it a more human place to be instead of dehumanising us, make it a more human place to be, where people can go inside to get well”** Service User

**“...a fresher building, a nice building so that they don’t feel like they’re human refuse”** Carer

... what you need is a secure hotel basically... country house hotel, that’s what we need...

...if you love and respect them, they get better so much more quickly. If somebody has dirt issues in a dirty environment, they can’t feel loved and respected, can they?

**...like retreat houses for people who were in the early stages and did need to get away, you know, like the monks used to have...**

... a crisis house that would be there as a refuge... but it would have to be staffed and the calibre of treatment a lot better than we have at the moment...

## The community services of the future

Users in particular talked of the need for more drop-in centres or day centres which they could access at all times and use for support in order to avoid the need for hospital. The centres they described began to look quite different to existing day services, in terms of accessibility, acceptability and availability. They discussed the need for centres to be open and accessible at all times – perhaps even 24 hours a day – so that people could ring and ask for advice during the evenings, nights and weekends. Again, they felt it should not be necessary to be on CPA to access these services. People talked of accessing information, support, advice and therapy, as well as a place of safety and access to recreational activities:

**“I’d still have day services and drop-ins and maybe courses within them”** Service user

**“So, if there’s more places like this [day services] where you can go to for help and support, it stops people from going into hospital”** Service user

**“If you could have enough funding to be open seven days a week and even during evenings and weekends, if there was a phone line we could ring for support on the phone”**

Service user

One significant aspect of this was the suggestion that centres provide opportunities for carers to gain education in mental health and for service users to learn about ‘self-management’.

The dilemma often discussed - of day centres potentially becoming mental health ‘ghettos’, a form of social exclusion in themselves – had its expression in the views of people using a Rethink service. They valued the day centre as a safe place away from a potentially hostile or uncaring community:

**“we come to [Rethink resource centre] because other people are here ... we all know what mental health’s about. We all come to meet our friends and they’re never judgemental but they know exactly where you are, if you want any support... if you went out into the community, who would be out there, who would be there to support us out there?”** Service user

In *Mental Health in the Mainstream*, this concept is developed a little further (pp74-76). Rankin envisages Community Health Centres which would offer people a neutral, non-medical space; they would be hubs of information, supporting people to ‘self-help’ on all health problems and links to established initiatives such as self-management and the Expert Patient Programme.

## Access and accessibility

A key function that this fantasy day centre could provide was access to help when it is needed, and for this reason some people suggested a phone line as part of the service or as an adjunct to it.

Many people were keen to suggest alternatives to the GP as first port of call and as gatekeeper to other services and treatments. They based this on past and present experiences, and suggested alternative arrangements. These included telephone helplines, and the use of alternative day centres as access points, as mentioned above.

**“it could be, maybe, a nurse coming out. It could be regular appointments, like, you don’t actually have to go to a GP. But there could be a centre – you could access it twenty four hours a day.”** Carer

Access workers based within Community Health Centres is the suggestion put forward in Mental Health in the Mainstream. Such a service would be resourced to provide a level of initial assessment and crisis response where necessary so there would need to be the relevant links to GPs and crisis teams as well as other mental health services. This discussion, in one group, moved on to touch on self-management and the value for the service user of learning ways of managing their symptoms and life for themselves.

### Self-management

**“I think we need to move more towards the patient actually learning to look after themselves: learning their problem, their symptoms, their behaviour and nipping it in the bud before it becomes a crisis.”** Carer

This theme was also raised by service users, who felt that one role of the fantasy day centre would be to provide them with the information and resources to take more control:

**“Looking after yourself, positive thinking, having a routine, maybe just doing one thing at a time. Sort of, looking at yourself, learning about yourself and actually seeing right in a crisis and ‘how do I actually get there?’. Look at it, to be aware of what’s happening.”** Service user.

### Support at home

People talked about the value of support at home and what they would like this to look like. It was not what everyone wanted, but for those who were in favour of home visits by professionals, it was often the regularity and the timeliness of support that was valued, as well as the opportunity for professionals to meet and engage with family members.

**“If you call them up, if you’re in a crisis, they will come out and see what your needs are and whether or not you need to come into hospital or if they need to give you support out of the hospital but more intensive support... maybe an hour or two hours a day.”** Service user

Of course, this sounds remarkably like the existing crisis resolution or home treatment teams. However, one or two people had negative experiences of these – teams visiting and checking only that someone has taken their pills before leaving – and one or two were not keen on home visits because of their concern about privacy and personal space. This emphasises the need for some degree of choice in the services provided and the way in which they are delivered.

**“There should be special trained medical staff like nurses... who should be visiting regularly, and that should be the contacting point in case there is an emergency. They could contact that person as quickly as possible and provide... what that person needs”**

Service user.

**“You could obtain a number to ring where you could talk openly to somebody who knows about mental health and perhaps would then signpost you on to whatever you decide to go and see, like the GP or psychiatrist.”** Service user.



Rethink runs 40 employment and training services to help people return to work. In all employment services, each member of the service has a detailed assessment based on what they want to achieve which forms the basis of a stepped plan. This identifies how the service will support people to enhance their confidence and build on their abilities and interests and develop work and job search skills in order to achieve their goals.

Rethink is a member of the Shift initiative run by the National Institute for Mental Health in England. Shift is developing programmes to work with employers to break down job discrimination and offer support to employers.

To find out more about Rethink employment services contact: 0845 456 0455. Email: [info@rethink.org](mailto:info@rethink.org) or visit: [www.rethink.org](http://www.rethink.org)

To find out more about Shift, contact: 0113 254 5127. Email: [info@shift.org.uk](mailto:info@shift.org.uk) or visit: [www.shift.org.uk](http://www.shift.org.uk)

Getting involved: If you commission services in your area and would like to talk to Rethink about our employment or our range of other services, contact: 0845 456 0455. Email: [info@rethink.org](mailto:info@rethink.org) or visit: [www.rethink.org/services](http://www.rethink.org/services)

### 3. How might services better support people into employment?

Employment is high on the agenda of the current initiatives towards social inclusion. The report from the Social Exclusion Unit (ODPM, 2004) highlights the need to find ways of enabling people with mental health problems to enter and remain in the workplace. People with long term mental health problems are less likely to be in employment than people with other disabilities (21% compared to 49% of all people with disabilities; DWP, 2001). Furthermore, employers state that they are more reluctant to employ people with a mental illness diagnosis than people with other disabilities (DWP, 2001). In this study we wanted to invite the views of service users and carers about how future services and employers might best support people into work.

#### Support into the workplace

Service users and carers were asked in these focus groups what changes they felt would need to be made to ensure that service users were able to gain meaningful employment more easily. Many of the usual routes to employment were discussed, including the possible need for service users to adjust to working full time, by means of a gradual process of trying out volunteering and part time opportunities.

Both service users and carers each spoke of the need to have a single designated worker who could help the service user to gain employment and subsequently support them in the workplace:

**“Every employer should have someone who was trained in mental health that could support the person if they become unwell at work.”** Service user

**“I think there’s a need for a sort of midwife first to gain the employment and then to marry the bridge between the non-working condition and then once in employment there is a need for a counsellor or buddy there.”** Carer

One or two people were keen to emphasise the need for on-going support, due to occasional periods of illness or difficulty: that withdrawing support too soon might prove to be a problem.





“The government needs to support employers financially, because people will be ill regularly and employers will need somebody to come in and replace them for short periods of time” Carer

“By the nature of the illness [service users] would have periods where they are not able to function and maybe their timekeeping won't be as good someone else's that hasn't got that illness, so all these things need to be taken into consideration by the employers really”. Carer

### Employment and benefit structures

Carers spoke about the need for the government in the future to allow employers the ability to provide flexible working hours for service users with the benefit of financial recompense for employers

They further pointed to the barriers presented by the benefits system as needing reform if service users are to feel relaxed about attempting to re-enter the job market.

**“...a more humane approach to benefits plus work, because nobody's going to be very encouraged who's not feeling a hundred per cent if they know they're not going to get their benefit if they [leave]...”** Carer

### Employer attitudes

However, a key issue was the stigma and discrimination people had experienced and continued to anticipate. In the future, both service users and carers felt there was a need to change employer attitudes, and many felt that this would only emerge once public stigma and attitudes more generally in society change significantly. Many service users felt despondent about the prospect of returning to or gaining paid employment:

**‘I think you're always going to have discrimination even if they say that you're not allowed to discriminate.’** Service user

Service users were reluctant to disclose their mental illness to employers, and needed assurance that there would be understanding before doing so.

**“I think they should start to work as a volunteer or job trial or.. doing some training courses... to gain experience”**

Rethink runs 53 carers services, providing information, individual and group support.

Rethink also runs 140 local support groups where members come together to share experiences and to learn from each other.

The Sheffield Carers Support and Development Service provides advice, information and support for carers through one-to-one support work, facilitator-led carers support groups, and carers' advocacy. As well as providing support for carers, staff develop and deliver training for mental health professionals to assist them to work in partnership with carers.

Three Carers Support services are dedicated to black and minority ethnic community carers in Kent, Birmingham and Bristol.

We also publish a wide-range of research on the experiences of carers and rights-based and information materials, including a carers website at: [www.rethinkcarers.org](http://www.rethinkcarers.org)

To find out more about our Rethink carers services, research and publications, contact: 0845 456 0455. Email: [info@rethink.org](mailto:info@rethink.org) or visit: [www.rethink.org](http://www.rethink.org)

Getting involved: If you would like to support Rethink's work, why not become a member? We operate a Pay What You Can scheme, so there are no financial obstacles to joining. To find out more, contact: 0845 456 0455. Email: [info@rethink.org](mailto:info@rethink.org) or join online at: [www.rethink.org](http://www.rethink.org)

Rethink has published a toolkit on dual diagnosis for practitioners and a leaflet for friends, carers and families. See [www.rethink.org](http://www.rethink.org)

## 4. What would support a better quality of life for carers?

Both service users and carers were invited to share their ideas about ways in which a better quality of life might be promoted for carers in the future. Most of the themes that emerged from this are not new, in the sense that they have been heard many times before, suggesting that they have yet to be fully addressed. Carers were asking for better information, communication and support and still often felt excluded from the system that was supposed to be caring for the service user in their care.

### Recognising carer expertise & knowledge

Carers expressed strong concerns in relation to feeling valued and respected by professionals. Professionals need to recognise that carers hold valuable information that they could benefit from but mutual trust needs to be established. They wanted professionals to recognise that "We know the person better than anybody".

**"It's not just a matter of education, it's knowing the little things.... this is what they're like and they do this and they do that, but somebody who's a carer that's dealt with it would see even little, tinier things"** Carer

Carers believed that if future mental health services listen to them, people experiencing a severe mental illness will have better prospects for recovery through quality care and treatment. In this context they gave a different perspective to confidentiality in mental health care. Some said they are sometimes reluctant to share the knowledge and information disclosed to them by the people they care for with professionals, for fear of service users being judged unfairly. They felt that the quality of care could be improved in the future if this aspect of information sharing could be considered by professionals showing empathy and consideration:

**"We want a two way exchange of information between (the carer) and the psychiatrist."** Carer

### Empowering the carer voice

Carers made a very strong point in relation to communicating with professionals and establishing an equal place in the mental health system:

**"What I would like to see is full and equal acceptance as a member of the care team"** Carer

**"The carer's view should 99% of the time be taken as part of the diagnosis"**. Carer

For this to happen, they felt that they needed training in negotiation and communication skills for dealing with professionals. They described wanting to know how to work the system to the right effect and how to be heard.

**"When I speak to a GP they're looking at me, poor old thing, you're ill too....I don't want that, I want to be heard"**. Carer.

### Support for carers

Both service users and carers identified the need for respite care:

**"I think [carers] should have respite so that they can go somewhere, even if it's just for a holiday."** Service user

Some carers expressed the common view that as long as the person they care for is supported then their own personal needs are being met. In other words, 'If they're ok, I'm ok'. In the future they wanted to be given information about the person they are caring for, to be given the knowledge, information, skills and strategies for coping:

**“My scary moment was when my son was discharged from hospital ... and I didn't know what on earth I was meant to say or not to say ... to not spark off another crisis, to not trigger it off. And I had absolutely no information at all from anybody...” Carer**

Carers described their desire for one to one access to professionals who will recognise that they have their own personal support needs, in relation to the situation in which they are the carer. One or two people talked about wanting access to skilled therapy to teach positive thinking and behaviour that can be applied when supporting the person they care for. As one carer said:

**“I go [to therapy] because it helps me be positive because I'm going to the hospital to see my son who is negative and he can't always help that because if he's got schizophrenia, hearing voices or whatever, or because he's in there, he's got every reason to be negative. I need to be positive, I need to be extra positive.” carer**

This goes beyond carer support groups and requires intensive professional counselling support for carers. As one carer said:

**“You need to remember who you are” whilst under the pressure of knowing that “you are person who is tied to them, keeping them on a level”. carer**

At the same time carer support groups were recognised as a valuable source of support that should be provided more consistently in the future; many carers valued this as often the only place in which they feel safe to share their experiences and feel understood by others.

## Dual diagnosis

Many carers expressed strong views that the mental health system in the future must offer addiction management services in order to manage – and help carers manage – the ongoing and increasing challenge presented by people with a dual diagnosis.

**“Take away the mystique of who these dual diagnosis people are and tell us how they're handling it, give us some of those skills... empower us with knowledge”. Carer.**

One of the carers' groups talked at length about this issue and went into some depth about the difficulties they faced and the needs they had for improvements in care and treatment .

**“I think [carers] should have respite so that they can go somewhere, even if it's for a holiday” Carer**

Rethink's new User and Carer Involvement team is establishing a network of user and carer activists and offering a range of training and support to people directly affected by severe mental illness who want to become more involved in the running of Rethink and the work that we do.

Rethink publishes a wide-range of policies, developed with service users and carers, on subjects from accommodation to welfare benefits and from assertive outreach to young carers.

Rethink campaigns against stigma and discrimination. We are working with the Institute of Psychiatry on a long-term anti-stigma programme to develop successful interventions with school-age children, police officers, medical students and trainee psychiatrists.

In 2006, Rethink will be running two Rethink Anti-discrimination Sites to test large scale public interventions to combat stigma, using powerful advertising and media initiatives.

To find out more about Rethink's User and Carer Involvement programme, our policies and our anti-stigma work, contact: 0845 456 0455. Email: [info@rethink.org](mailto:info@rethink.org) or visit: [www.rethink.org](http://www.rethink.org)

Getting involved: If you want to get involved in combating stigma in the media by using your own experiences, why not become a Media Volunteer? To find out more, contact: 0845 456 0455. Email: [info@rethink.org](mailto:info@rethink.org) or visit: [www.rethink.org](http://www.rethink.org)

## 5. Overarching themes

Over the course of the discussions, two significant themes emerged both of which had implications across all of the issues addressed: service user consultation and stigma and discrimination.

### Service user consultation: policy versus reality

Service users expressed concerns that current consultation and involvement methods were meaningless and tokenistic. People described taking part in meetings that were promoted as consultation processes but were actually just communication vehicles for decisions that had already been taken. Service users in one group expressed concern that when decisions are taken regarding the provision of mental health services, politicians and managers responsible for these decisions should be aware of how their actions affect people on the ground. In particular, they should recognise the damaging effects of repeated change at political level:

**“I would like the government to be aware of their decisions, how it affects us on the ground. It's very fine, a politician saying, ‘OK in the mental health sector we have to have this done’, but they have to realise that the bottom line is us that have to carry that plan forward. And it's not always a practical thing to do, it's not always possible and sometimes it's very upsetting and sometimes their decisions make people ill because they're so worried about these decisions that have been made”.** Service user

Service users felt that the future should offer real opportunities for people affected by severe mental illness to influence change and be heard by decision makers:

**“Give us our voice back”.** Service user

Services supporting people with an existing mental illness should enable people who are further along with their own recovery to take part in the planning, delivery and review of services. The point at which people leave a service should be flexible and the service user should be listened to at this point. Professionals should support service users to develop a collective voice with real power. Political decision makers should ensure they are aware of how their policies impact at the grassroots. Voluntary organisations might more closely reflect the voice of service users in the future:

**“I was wondering whether there may be something in there about future roles for charities, organisations like Rethink where maybe in 50 year's time the people within the organisation are all people with direct experience.”**

Service user

### Stigma and discrimination

Perhaps the strongest feelings expressed by both service users and carers in these groups concerned the need to achieve a fundamental change in attitudes towards people with a diagnosed mental illness and their carers. They had found negative attitudes amongst mental health professionals in community teams and inpatient wards, GPs, benefits agency officers, the media, the general public and potential and actual employers.

They said that for many of the changes they envisaged to take place, for their vision of mental health to become real, attitudes would need to change within services as well as in society at large, and the stigma associated with mental illness would need to be substantially reduced.

**“and I think the world in general needs a great deal of education as regards mental health... you know, they’re just so ill informed, this is part of the stigma problem, if you like.”**

Carer.

**“I think [professionals] should stop looking down on us, that’s what they are doing, they look down on us.”**

Service user

**“...we feel, like, this big sometimes. They don’t treat us as human beings. We’re not just parents of that particular child or relation or whatever it is, or a husband or mother, we are individual persons. And we’re none of us stupid...”**

Carer.

The need for a significant change in attitudes with regard to mental illness is in no way unique to this study. The Social Exclusion Unit report (ODPM, 2004) gave this as the first main cause of social exclusion:

“Stigma and discrimination against people with mental health problems is pervasive throughout society. Despite a number of campaigns there has been no significant change in attitudes.”

Indeed, this issue has arisen over and over again in reports, studies and local groups, as having a significant effect on people’s lives. Some of the carers in this study felt that stigma needs to be addressed from a very early age, as young as three when children are at nursery and beginning to become aware of each other’s differences. Children can be taught to understand everyone is different and to appreciate if not celebrate diversity. Some discussion addressed the difficulties of removing stigma: on the one hand, maybe 2,000 years would not be enough to do so, but on the other hand, several people were encouraged by progress over recent decades in talking more frankly and publicly about cancer and HIV/Aids.

**“The staff have to be aware, they would have to be aware of mental illness, and if you need to talk to somebody, they would have to be people that you could talk to... would have to be – compassionate”** Service user

**“They come in, they talk among themselves and they go back home again and that’s it. You’re left on your own again”** Service user

**“I think [professionals] should stop looking down on us, that’s what they are doing, they look down on us.”**

Service user

Rethink is involved in a wide-range of national and local campaigns that lobby for change and improvement within mental health as well as putting our values and beliefs into practice each day in our services.

This report is part of our Mental Health First programme that seeks to hold the government to account for its present reform programme and develop new areas for improvement that place mental health in the mainstream of health and social care reform.

To find out more about Rethink's Mental Health First programme, our campaigns and our lobbying work, contact: 0845 456 0455. Email: [info@rethink.org](mailto:info@rethink.org) or visit: [www.rethink.org](http://www.rethink.org)

Getting involved: If you want to get involved in improving mental health and making sure that it is in the mainstream of health and social care reform, why not become a Campaigns Volunteer? To find out more, contact: 0845 456 0455. Email: [info@rethink.org](mailto:info@rethink.org) or visit: [www.rethink.org](http://www.rethink.org)



## 6. Transformation and Choice

**“So, in many ways, it seems the ideal situation is much more to do with recognition and respect.” Carer**

If we look at the themes that emerged from our focus groups more closely, we can see that they have strong similarities to the standards proposed in the National Service Framework (Dept of Health, 1999; see Appendix B). Thus, it could almost be argued that the service users and carers we spoke to were asking for nothing more than delivery of the National Service Framework. The NSF states that people should have round the clock access to services, be able to have their needs identified and assessed, be offered effective treatments and access to a hospital bed or alternative where appropriate. They should receive care that ‘optimises engagement’, prevents a crisis and reduces risk. Standard 6 states that carers should have an assessment of their own needs and a care plan implemented in discussion with them.

Indeed, as one carer pointed out:

**“Theoretically, we’ve got a lot of these things now. They’re just not good enough. The thought is there, the concept’s there but the reality doesn’t meet the concept.”**

What, then, are the differences – the significant elements of the vision – put forward by the service users and carers who took part in our focus groups? The most significant proposals they made for service provision concern the conceptualisation of a crisis house or place of safety to replace reliance on hospital care and suggestions for alternative access. Both of these are further expounded in the vision put forward in the final report to emerge from the Mental Health First programme: *Mental Health in the Mainstream* (Rankin, 2005). The accessible multi-purpose day centres described by service users and carers in the focus groups appear in the above report as follows:



'In every community there is a Community Health Centre where people can get advice on all aspects of health, including mental health. In these centres there are access workers with whom people can discuss their health concerns. The access workers offer information about different ways to improve and maintain mental health such as exercise, reading and volunteering...' (Rankin, 2005)

As this quotation suggests, Mental Health in the Mainstream envisions a new and innovative approach to accessing services, through a 'renewed focus on primary care and community health' and a role for access workers and community health centres. It also discusses re-focusing inpatient services through the formation of crisis units making greater use of advance directives or crisis plans than is the case at present.

One of the key themes of the work programme – and the subject of the third working paper – was choice. It is acknowledged that choice is problematic in mental health, an arena where compulsory detention and treatment are possible and historical attitudes would hold someone with a mental illness diagnosis as incapable of making rational choices or decisions for themselves. Nevertheless the paper contends that choice has the potential to transform mental health services through improving therapeutic relationships, creating greater variety in services and establishing services with greater cultural relevance. The paper concludes with two key recommendations:

- **New access points to good mental health**
- **Personal recovery budgets**

There is no doubt that the service users and carers who took part in these focus groups would strongly support these. The second (personal recovery budgets) outlines one of the means with which to bring about choice in practice, which was not a focus of the present research (although many people did mention the present lack of resources or the need for more resources in the future).

“and in 50 years time I think the culture will recognise that, there won't be the stigma to the same degree as there is today... the culture around will be more accepting of people in the community than it is today” Carer





## 7. The Vision: Respect and Acceptance

The vision put forward by service users and carers is founded on a fundamental improvement in public and professional attitudes towards people with a diagnosis of mental illness. Both service users and carers were emphatic about the difficulties they faced with current stigma and discrimination, both in public contexts and within mental health and social care services. The other changes they wanted to see needed to go hand in hand with a significant change in attitudes.

**1. A comprehensive and fully funded national anti-discrimination programme owned by the mental health community.** For many of the people we spoke to, this was as important as any of the elements of service provision they wanted to see in future mental health care: to be treated with respect and valued as an equal human being was at the heart of their vision for the future.

**2. New and accessible routes into care.** Many people had found their GPs to be inadequate or uninterested in mental health. They were seeking something innovative and comprehensive, perhaps in the form of entirely re-focused day centres or 'Community Health Centres' where they could access many forms of information and advice as well as help in a crisis.

**3. Alternatives to inpatient care.** Service users and carers, inspired by the permission to invent something new, described therapeutic environments in the form of crisis houses, retreats or hotels, where people would feel cared for and be listened to, and have more treatment options available to them. Whilst carers were more reluctant at first to consider an alternative to hospital wards if it meant a reduction in beds available in a crisis, they conceded that current conditions are unacceptable and rose to the challenge of re-inventing them.

**4. Modernising day services.** The people we spoke to envisaged a more open, accessible and engaging form of day centre or resource centre for the future, a place where people can access help, information and advice as well as be signposted to where additional help can be obtained. These may be similar to the 'healthy living centres' of the 1990s and may become the Community Health Centres or connected care centres of the 21st Century.

**5. Support and recognition for carers.** Carers want to be seen as part of the mental health team when their role is to care for someone with a mental health problem. Service users, too, saw a need for more support in the form of respite care.

**6. Opportunities for employment.** Service users were keen for the development of opportunities for them to gain or regain paid employment. Carers were in some cases more cautious about this, and pessimistic about employers' attitudes.

**7. Making a difference.** Both service users and carers wanted to have more say in the future of mental health services, in the planning and delivery as well as the individual experience of care. They expressed dissatisfaction with current systems for involvement or consultation: service users felt that they were often tokenistic and carers frequently felt excluded. Both wanted their voices heard more powerfully and acted upon where possible, although they recognised that this would not always be possible.

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# Appendix A

## The Focus Groups

Rethink undertook a series of six focus groups with service users and carers in partnership with the Institute of Public Policy Research (ippr) to explore how people might envisage mental health services in the future. The aim of the focus groups was to inform the ippr report due to be published in spring 2005.

All of the groups were linked to existing Rethink carer and service user groups; three were carried out with service users and three with carers. Due to time and resource constraints the project was limited to southern areas of England but we ensured that the groups engaged with people from diverse backgrounds in relation to ethnicity, urban/rural localities, age, background and experiences. One group was held with service users in a South Asian mental health project assisted by an interpreter. Group attendance ranged from 4-10 people with a variety of community venues being used. Each group was facilitated by a lead person from Rethink or the ippr and was supported and observed by a second facilitator. The facilitators put three main scenarios to the group and probed with supplementary questions in order to draw out responses from all of the participants. The three main scenarios were based on the future of mental health services, envisaging some 20, 30 or 50 years hence:

1. What might services look like without the provision of inpatient wards?
2. How might services better support people into employment?
3. What would support a better quality of life for carers?

Every group session was recorded and later transcribed to provide a full record of the discussion. The data from all groups were then analysed and reviewed by a Rethink-led project group from across the Research and Campaigns departments.

# Appendix B

## NATIONAL SERVICE FRAMEWORK FOR MENTAL HEALTH (Standards Two to Six)

### Standard Two

Any service user who contacts their primary health care team with a common mental health problem should:

Have their mental health needs identified and assessed  
Be offered effective treatments, including referral to a specialist for further assessment, treatment and care if they require it.

### Standard Three

Any individual with a common mental health problem should:  
Be able to make contact round the clock with the local services necessary to meet their needs and receive adequate care  
Be able to use NHS Direct, as it develops, for first-level advice and referral on to specialist helplines or to local services.

### Standard Four

All mental health service users on the Care Programme Approach should:  
Receive care which optimises engagement, prevents or anticipates crisis, and reduces risk  
Have a copy of a written care plan which:  
Includes the action to be taken in a crisis by service users, their carers and their care co-ordinators  
Advises the GP how they should respond if the service user needs additional help  
Is regularly reviewed by the care co-ordinator  
Be able to access services 24 hours a day, 365 days a year.

### Standard Five

Each service user who is assessed as requiring a period of care away from their home should have:  
Timely access to an appropriate hospital bed or alternative bed or place, which is:  
In the least restrictive environment consistent with the need to protect them and the public  
As close to home as possible  
A copy of a written after care plan agreed on discharge, which sets out the care and rehabilitation to be provided, identifies the care co-ordinator, and specifies the action to be taken in a crisis.

### Standard Six

All individuals who provide regular and substantial care for a person on CPA should:  
Have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis  
Have their own written care plan, which is given to them and implemented in discussion with them.

# rethink

severe mental illness

For more information on Rethink,  
and the services it offers to service users, contact:

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Rethink publishes an extensive range of publications for service users including *Only the Best*, a guide to getting the best fit medication and *What Is Severe Mental Illness?* To order copies or to find out more about Rethink's publications call 0845 456 0455 or log on to [www.rethink.org](http://www.rethink.org).

If you feel it is important that Rethink continues to speak out about the issues dealt with in this report why not become a Rethink member and help us speak out for everyone affected by severe mental illness. Call 0845 456 0455 or join online at [www.rethink.org/membership](http://www.rethink.org/membership).

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