

"I have a wonderful life waiting for me, whenever I can climb out of the deep, deep, deep well of dark despair"



Just one per cent

The experiences of people using mental health services

June 2003

rethink
severe mental illness

Preface

The government is committed to increasing “patient” involvement in health-care. It appears regularly in the plethora of consultations, strategy papers and structural changes taking place in the NHS.

Mental health is the only area of health-care where compulsion and “being done to” are run-of-the-mill experiences for hundreds of thousands of people. Involvement and representation means much more than being given seats on Primary Care Trusts or being consulted on the colour of the day-care room.

It means being seen first and foremost as a whole person with the same need for respect as anyone else. It means being listened to and valued in decisions regarding one’s own care. It means ending the blight of prejudice, ignorance and fear that gives rise to the stigma and discrimination endemic in mental health. It means tackling the fact that just one per cent of service users are satisfied with their current quality of life.

Just One Per Cent presents the views of the “real experts” - people with, on average, 17 years of being on the frontline, 17 years of being “done to.” If these findings are surprisingly optimistic in places or, perhaps more frequently, still disturbing, it is because mental health services and attitudes to the people who use them are in a state of flux.

The challenge confronting Rethink is to help create an environment where people using mental health services derive real benefits from representation and involvement - reversing the 99 per cent dissatisfaction rating.

We are grateful to our survey partners - the Institute of Psychiatry, Depression Alliance, Manic Depression Fellowship and Carers UK for their support and to Lundbeck Ltd for funding the publication of this report.



Robert Banner, chair, Rethink



Cliff Prior, chief executive, Rethink

Introduction

Survey method

Rethink regularly carries out social survey research to monitor expert opinion on standards of mental health care. The recent Our Point of View survey, upon which this report is based, asked are things getting better for the people who use mental health services, their families and friends at the beginning of the 21st Century in Britain?

Two versions of the survey were developed, one for carers and another for service users. Who Cares? - the first in this series of reports - looked at the experience of carers and is now available. Just One Per Cent looks at what service users want in order to feel fully represented. More reports are planned using other aspects of the survey data.

Rethink, and its survey partners, sent out approximately 20,000 copies of the nine-page service-user questionnaire. We received 3,033 replies. The analysis presented in the report is based on summary statistics and the coding of open-ended questions. The quotations used are selected extracts from the survey.

Who responded to Our Point of View survey?

A summary description of our survey respondents is provided in table one. The findings do not claim to be representative of all service users’ views but the survey has reached out to a broad spectrum of mental health service users with different health and social care needs and experiences. For example, 19 per cent of the sample had been supported in hospital in the last year while 3.5 per cent have never had any contact with mental health professionals. Approximately 55 per cent of our sample live with a diagnosed severe mental illness and 31 per cent with depression.

Table one: Respondent summary information

Gender (n=2998)			
1253 - Male (42%)		1745 - Female (58%)	
Ethnic origin (n=2983)			
2715 - White British (91%)			
Average age (n=2972)		Age range	
46 years old		16 – 90 years	
Region (n=2933)			
South West	424 (15%)	Eastern	388 (13%)
South East	625 (21%)	Midlands	531 (18%)
Greater London	321 (11%)	Northern	380 (13%)
Other (Wales, Scotland and Northern Ireland)		264 (9%)	
Length of contact with mental health system (n=2736)			
Mean average	17 years since first contact with mental health professionals		
Range	1 to 65 years		
106 people (3.5%) reported they had never had contact with a mental health professional (e.g CPN, social worker, psychologist, psychiatrist)			
Knowledge of current diagnoses (n=3033)			
2715 people described their current diagnosis			
84 people have not been given a diagnosis or do not know their diagnosis			
234 no data provided.			
Main diagnosis (n=2715)			
80%	of sample provided one diagnosis only.		
90%	of sample agree with their mental health diagnosis		
Manic Depression	886 (33%)	Schizo-affective disorder	102 (4%)
Depression	848 (31%)	Personality Disorder	49 (2%)
Schizophrenia	466 (17%)	Psychosis	25 (1%)
Anxiety disorder	130 (5%)	Other	209 (7%)

(*n”= number of valid responses for each question)

People replying to this survey have, on average, 17 years of experience of using mental health services.

Sub-standard?

The National Service Framework for Mental Health ¹ was introduced by the government in 1999 to raise standards and reduce the postcode lottery of care.

Its seven "standards" stopped short of giving a legal right to care and treatment - despite the state retaining the right under the Mental Health Act (1983) to impose care and treatment. However, the National Service Framework was recognised as providing services with clear guidelines on the broad approach they should take to service development and delivery, and included clear routes for service users to represent their needs.

It is, therefore, shocking that in the intervening period:

- More than one in four people (28 per cent) report being shunned when seeking help.
- More than one in three people (34 per cent) do not have any written information about their mental health problem, local services or their treatment options

Indeed, of the two-thirds of people (66 per cent) who do have written information of some kind:

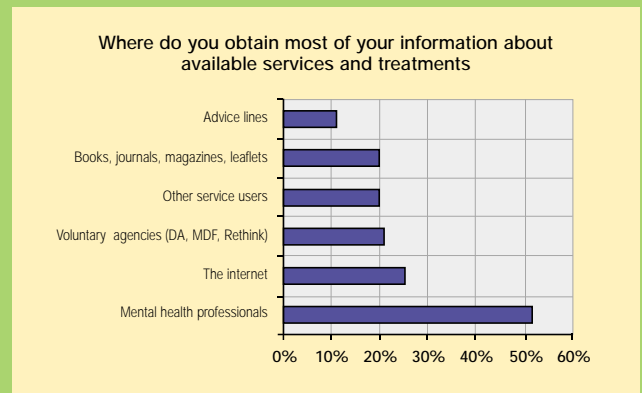
- More than one in three (36 per cent) only understand some of it
- One in 20 (5 per cent) understand none of it.

Nor is it the case that for those with at least some written information that it comes from an "official" source.

Mental health professionals are the source of information for just over half of service users (52 per cent). Others who have managed to access information have done so through a variety of sources (see figure one). It is not surprising in this context that one in three service users do not have enough information to support them in managing their own mental health problems.

"Mental health services can't deal with the amount of people. I had to find out myself using the net for information about mental health and how to find a counsellor"

Figure one: Keeping ourselves informed



One in four people have been turned away when seeking help in the last three years.

"I have a friend who nearly committed suicide last year, she did not get the help and support she needed"



Planning to care

The Care Programme Approach (CPA) was introduced in 1991 to overcome the lack of co-ordination in mental health that was leaving many people without the support they needed. Much has been written about CPAs and the complexity of their operation², but they rest on some simple foundations.

- First, the CPA 'care plan' should be written down, with the individual receiving the care and those delivering it having a copy.
- Secondly, the care plan should identify one individual, usually called a care or CPA co-ordinator, whose job it is to ensure that everything promised is being delivered.
- Thirdly, the person who needs the care and support should be involved in drawing up the care plan.
- Fourthly, care plans should be regularly reviewed and updated.

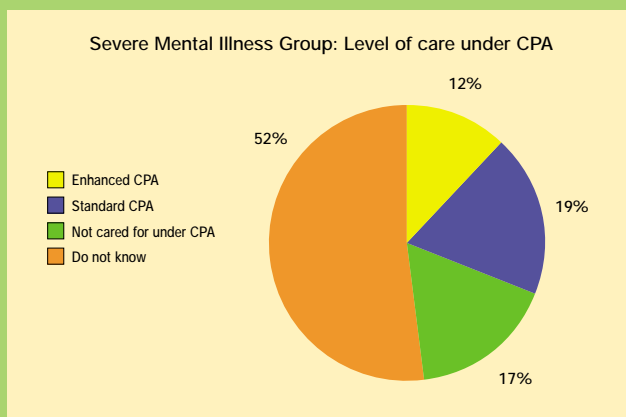
Standard Four of the National Service Framework's seven standards, insisted that all mental health service users on the CPA should have a written copy of the plan detailing the care available and how to access services "24 hours a day, 365 days a year." Our survey finds that, despite nearly four years of rolling out the National Service Framework, for those people with a diagnosis of severe mental illness - schizophrenia, manic depression, schizo-affective disorder, psychosis:

- 742 (52 per cent) don't know their level of care under the CPA (see figure two)
- 708 (48 per cent) don't have or can't be sure if they have a care plan
- 278 (19 per cent) do not know how to access any sort of help out of hours
- 217 (15 per cent) report the only help available out of hours is from family or friends

There is some good news. For the 718 people who do have a care plan, 90 per cent report having their views and preferences considered when their care plan was developed.

However, it is very unlikely that such a large number of people (48 per cent in our sample) with a clear diagnosis of a severe mental illness will not have a care plan. What is most likely, is that large numbers of people do not realise they have such a thing. They are not able to represent their views and needs in the drawing up of the care plans that govern the types of care and support they are able to access. Without this individual representation, the foundations of the CPA are undermined and the service user is unable to hold the professional to account for services that may be delivered poorly or not at all.

Figure two: Being well informed?



"Psychiatrist more open with me - a feeling of sharing common objective towards wellness, including more involvement in care plan"

"Care plans tokenistic, practitioners often long term sick, promises made not delivered, morale at all time low"

Over half of service users with a severe mental illness do not know, or cannot be sure, if they have a care plan.

Taking the pills

For over a decade Rethink has pressed for more modern medicines to be made widely available for the treatment of severe mental illness.

In 2002, the National Institute for Clinical Excellence (NICE) ruled that the postcode prescribing of newer medicines for the treatment of schizophrenia, which greatly restricted their availability in many parts of the country, must end. NICE also called for the needs and wishes of the service user to be fully represented when decisions were taken about prescribing ³.

Rethink's continuing Only the Best ⁴ campaign aims to provide service users and carers with the information they need to gain the full benefit of the NICE decision by insisting on regular reviews of the medicines they receive. It is also pressing all parts of the NHS to fully implement the NICE ruling, particularly its insistence on service user choice, and pressing the government to fully fund any additional costs that fall on the NHS.

In 2003, the government announced an inquiry into the latest generation of medicines used for the treatment of depression, known collectively as SSRIs, after claims that some produce side effects linked to suicide and other forms of harmful behaviour.

Rethink's earlier reports - A Question of Choice ⁵, That's Just Typical ⁶ and Doesn't It Make You Sick? ⁷ - drawn from service user and carer evidence presented to NICE, found widespread concerns about the availability, choice and side effects of medicines available for the treatment of severe mental illness.

Over 2,640 people (87 per cent) taking part in the Our Point of View survey, are currently taking one or more prescribed medicines.

Clearly, medicines are a real issue in mental health and on balance most service users feel their medication is helping (see figure three).

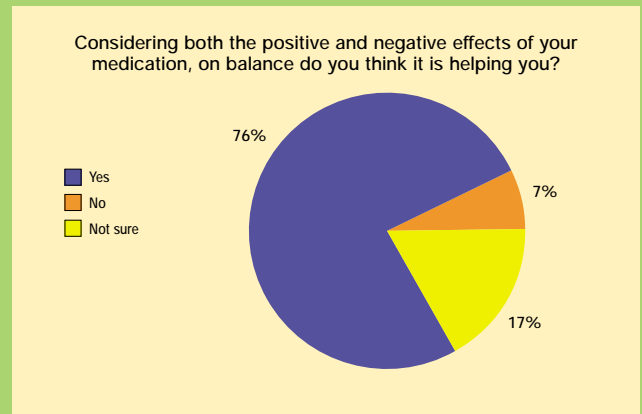
However, when asked to indicate their top three priorities for improving services (Table three, page six) nearly three in five people (58 per cent) included medicines with fewer adverse side effects. More than one in three (34 per cent) said that this was their top priority.

Only just over half of service users (53 per cent) always feel able to talk to their doctor or nurse about the medicines prescribed to treat their mental health problem (see table two). One in eight people (13 per cent) said that they had not had their prescribed medicine discussed or reviewed in the last year

On the positive side, as table two on this page shows, only one in 10 people (10 per cent) said that they never or rarely felt able to discuss medicines with their doctor. Indeed, 90 per cent of people felt able, at least some of the time, to talk to their doctor about their medicine

Just over half of service users always feel able to talk to their doctor about the medicines prescribed to treat their mental health problem.

Figure three: Benefits of medication?



“Having a long term medication that really worked, and stayed working all the time and not just some of the time, would really improve the quality of my life”

Table two: Involvement in medical decision

If you have a problem with your medication, do you feel able to talk to the person who prescribes it?		
Always	1381	53%
Most of the time	597	23%
Some of the time	373	14%
Rarely	174	7%
Never	76	3%

“I don't want to be dependent on medication to keep me stable, but to find another way to deal with my problems”

“Services are more user friendly and encourage user involvement which is a positive development”

Regular physical health check ups feature in the top three priorities for almost one in three of respondents.

Table three: Improving services

Priority area	Ranked as Top Priority	Ranked in Top 3 priorities
Medication with less adverse side effects	934 (34%)	58%
More GP training on supporting people with mental health problems	801 (29%)	43%
Less discrimination in the workplace	728 (27%)	46%
Greater access to talking and alternative therapies	662 (24%)	49%
Making it easier to make benefit claims	454 (17%)	32%
Being able to make an advance statement on treatment options	443 (17%)	35%
Having regular physical health check ups	409 (15%)	31%
Having more user-led services	375 (14%)	29%
Having access to an advocate	378 (14%)	28%
Provision of more independent accommodation	334 (12%)	25%

Note: respondents could rank more than one option as their ‘top’ priority.

“I need real therapy to find out what the real problem is. Did it start in childhood or just genetic?”

“To be able to afford to go out and meet understanding people. On low income it is very stressful to live. A TV licence is just under two week’s income - it is a fight to survive”

More than medicine

Less restricted access to modern medicines, greater choice and fewer side effects are not the only improvements sought by people who use mental health services.

Medicines are not the whole answer. Other interventions and services including quality support from non-specialist professionals such as GPs or greater provision of appropriate accommodation, can and do have a real effect on how people experience mental health services.

Service users taking part in this survey were asked to rank a series of mental health care “improvements.” These are set out in table three on this page.

Almost half of respondents (49 per cent) ranked talking therapies in their top three. Perhaps the best known of these, cognitive behavioural therapy or CBT, has a proven track record in depression and, in an adapted form, within schizophrenia. The National Institute for Clinical Excellence has recommended its wider use in schizophrenia, but long waiting times are reported across the country⁸.

More training for GPs was recorded a top priority by 29 per cent of respondents. GPs are often the first contact for people developing a mental health problem and their vital role, as part of the primary health care team, in identifying and assessing common mental health problems as well as being first referrers to specialist services for severe mental illness is recognised in Standard Two of the National Service Framework. However, there are very few GPs who undertake specialist training in mental health and many GPs are reluctant to intervene early. The new GP contract, which is bogged down in negotiations as we write, will carry a monetary incentive for GPs both to register people with a mental health problem and to provide regular physical health check ups. Regular physical health check ups feature in the top three priorities for almost one in three (31 per cent) of people.

Advance statements, which allow a person to set out, when well, how they want to be treated, when ill, are a first priority for 17 per cent of respondents. The government is promising that a new Mental Health Act will encourage their wider use, but has said that it will stop short of given them legal force, allowing the medical profession to over-ride the wishes of service users.

Access to an advocate, often present or past service users themselves, is a first priority for 14 per cent of respondents. Again, the government has promised to provide for the right of access to an advocate in a new Mental Health Act. However, the right of access will be limited to people being subject to compulsory treatment, leaving those - one in four in our survey - denied sought after treatment without anyone to support them in speaking out.

Respondents were also asked to list any other “improvements” in addition to those listed in table three. These additional priorities are set out in table four on page 7.

Just one in 100 people said that they were satisfied with their quality of life.

Change for the better

The ready availability of quality mental health services are necessary to maximise the opportunities of any individual recovering a meaningful and fulfilling life from a mental health problem. But they are not sufficient.

A holistic approach is required. Figure four shows the ideal. Person-centred, taking account of the person's rounded identity and every individual's need for social inclusion, this model is supported by the service users taking part in this survey.

The list of top three priorities (in table three on page 6) includes:

- Less discrimination in the workplace (46 per cent)
- Making it easier to make benefit claims (32 per cent)
- More independent accommodation (25 per cent)

Service users also want to be represented fully in the planning and delivery of services with 29 per cent placing "more user-led services" in their top three.

Almost a third of respondents (29 per cent or 879 people) added new priorities to the list offered. The most frequently cited additions are listed in table four. Over half of these (56 per cent) urged more and better quality mental health services with faster access and a greater level of involvement and respect from professionals.

But, again, non-medical improvements were also identified. Tackling stigma and discrimination through public education was a priority for 29 per cent of respondents, reflecting a key barrier to social inclusion and employment erected by the prejudice, ignorance and fear surrounding mental health.

When asked to name just one single change that would improve their quality of life 62 per cent of all respondents named a non-medical change, such as more money, improved social relationships and, again, an end to stigma and discrimination. The list of quality of life change options provided by respondents was long. Figure five summarises those most frequently cited.

Just one in 100 people (1 per cent) said that they were satisfied with their quality of life.

References

- 1 Department of Health (1999) National Service Framework for Mental Health. London: HMSO.
- 2 Schneider J, Carpenter J, Brandon T (1999) Operation and organisation of services for people with severe mental illness in the UK. *British Journal of Psychiatry*, 175: 422-425: Department of Health (2000) Effective care coordination in mental health services: a policy booklet. London: HMSO.
- 3 National Institute of Clinical Excellence (2002) Full guidance on the use of newer (atypical) anti-psychotic drugs for the treatment of schizophrenia (No. 43). London: NICE.
- 4 To receive a copy of the Only the Best report, please contact Rethink on 0845 456 0455
- 5 Hogman G, Sandamas G (2000) A Question of Choice. London: Rethink Publications.
- 6 Corry P, Hogman G, Sandamas (2001) That's Just Typical. London: Rethink Publications
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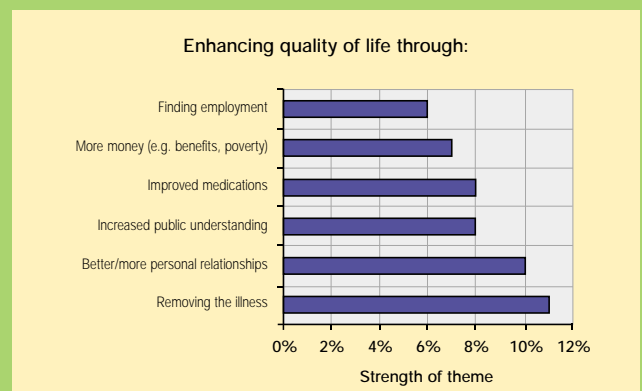
Figure four: A holistic approach to mental health



Table four: Improving Services - additional user rated priorities in addition to those in table three

Priority areas provided by respondents in addition to those listed in table four	Frequency (n=879)	Percentage
Public education, reducing stigma, removing discrimination, training for key audiences	259	29%
More (and better quality) mental health services required (e.g. more day services, out of hours services and befriending schemes)	211	24%
Improve access to mental health services (e.g. obtain help in a crisis, shorten waiting times to see psychiatrist, greater access to counselling)	176	20%
Improve relationships between staff and service users (e.g. greater respect for service user opinions, better communication)	104	12%
More support in the community (e.g. more support workers)	98	11%
Change approach to managing mental illness (e.g. emphasis on holistic understanding of mental illness, diet and nutritional work, reduce use of prescription drugs)	86	10%

Figure five: One change that would improve a person's quality of life



"More acceptance of mental health problems needed by public, particularly in employment field. Feel still strong stigma and problems over disclosure"



Recommendations

Service users should:

- have a legal right to care and treatment
- be able to specify in an enforceable advance statement what form this care and treatment should take
- be recognised as experts by experience
- be listened to, involved and represented in decision-making
- be involved in the drawing up of a care plan that meets physical and mental health needs and receive a written copy
- be able to talk to a mental health or social care professional on request

We are grateful to all the service users who took the time and trouble to complete the Our Point of View survey. Without their efforts, this research would not have been possible.

We are also grateful to our survey partners the Institute of Psychiatry, Depression Alliance, Manic Depression Fellowship and Carers UK for their support, and to Lundbeck Ltd for funding the publication of this report.

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Lundbeck's mission is to improve the quality of life of those who suffer from psychiatric and neurological illness and believes this is best achieved through investment in knowledge, research, education and holistic attitudes to patient care.

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.

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.



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