



For better  
mental health

**Not alone?**

**Isolation and mental distress**

The theme of Mind week 2004 is isolation. Isolation could be feeling cut off from other people or not having as much contact as you would like, or being left out of family and other relationships, social life and recreation or work (paid or unpaid).

Previous research by Mind has found that people with mental health problems experience astonishing levels of discrimination and stigma in many areas of life. This year, Mind commissioned a survey of mental health service users to examine how isolated people with mental health problems felt, to explore the causes and triggers, and to find out how people overcome isolation.

To complement Mind's survey of people with mental health problems, a National Opinion Poll (NOP) of the general public was also carried out, to investigate whether patterns of isolation seen in people with mental health problems were reflected in the general public. The questions also sought to discover public perceptions of the causes and solutions of isolation.

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## Not alone? Isolation and mental distress

### The Mind 2004 survey

In February 2004, 6,789 questionnaires were sent out to all of Mind's networks.<sup>1</sup> The networks are made up of members of Mind Link, Diverse Minds, Mind in Action, Rural Minds, Welsh-based networks and 209 local Mind associations.

#### Profile of Mind survey respondents

Gender	Per cent
Female	49
Male	27
Did not answer	24

Ethnicity	Per cent
White British	80
White Irish	1
White other	4
Asian or Asian British	2
Black or Black British	2
Mixed race	2
Other ethnic group	2
Did not answer	7

Respondents in these networks have experience of mental distress. By 16 February 2004, 532 completed questionnaires had been returned, a response rate of around eight per cent. The survey was also available via Mind's website and 24 questionnaires were obtained this way.

Age ranges	Per cent
18 to 24	5
25 to 34	18
35 to 44	27
45 to 54	25
55 to 64	15
65 to 74	5
75 to 84	1
85 and over	0
Did not answer	4

Area type	Per cent
Large town or city	47
Small town	31
Rural area	13
Other	3
Did not answer	6

### The National Opinion Poll (NOP) survey

Over the period 12 to 17 February 2004, NOP conducted face to face interviews with a representative sample of 964 members of the public. Respondents were asked:<sup>2</sup>

1. Have you ever felt isolated?
2. Even if you have never felt isolated, what do you think are the three main reasons people can feel isolated?
3. If someone were feeling isolated, what three things do you think would help them overcome their feelings?
4. Thinking about different groups of people in our society today, can you tell me which three of these groups of people, if any, you think feel the most isolated in our society today?

- A. Old people.
- B. People with mental health problems.
- C. People with physical health problems.
- D. People with hearing or sight loss.
- E. Asylum seekers.
- F. Ex-offenders.
- G. Bereaved people.
- H. Students.
- I. Homeless people.
- J. People with poor health in general.
- K. Executives.
- L. Celebrities.

Other answer (specify).  
None of these.  
Don't know.

### Key findings

- Eighty-four per cent of people with mental health problems have felt isolated (Mind survey) compared to 29 per cent of the general population (NOP survey).
- Young people were the most isolated age groups in both surveys: 92 per cent of 18 to 24 year olds with mental health problems and 35 per cent of adults aged 15 to 24 in the NOP poll felt isolated.
- People living in rural communities and from Black and minority ethnic communities are also more susceptible to isolation.
- Geographically, people in East Anglia (35 per cent), Yorkshire and Humberside (34 per cent) and the South East (33 per cent) are the most isolated in the UK. People living in the North seem to be the best supported as 83 per cent of respondents said they had never felt isolated (NOP survey).
- For the vast majority (77 per cent) of respondents to the Mind survey, lack of understanding by others about mental health issues was a key cause of isolation. There does seem to be recognition of this amongst the general public. Forty-five per cent viewed people with mental health problems as the most isolated group in society, second only to older people (NOP poll).
- Over two thirds of people with experience of mental distress report that isolation causes or contributes to their mental health problems.
- Of respondents to the Mind survey, 80 per cent felt that isolation made it harder for them to recover or cope with their mental health problems.
- Fifty-eight per cent of people with mental health problems find that isolation is linked to discrimination on grounds of mental health.
- Relationship problems because of mental health problems (74 per cent) or lack of close relationships (71 per cent) were cited as some of the top causes of isolation in the Mind survey. The general public too is more likely to experience isolation if living alone (NOP survey).
- Unemployment (54 per cent), lack of money (59 per cent) and lack of support services (57 per cent) all featured highly as circumstances leading to isolation according to Mind's survey of people in mental distress.
- Solutions to isolation are not always complex or difficult to attain. The single most mentioned support in overcoming isolation was ready use of a phone – cited by 55 per cent of respondents in the Mind survey. However, one in ten didn't have ready access to a telephone.
- Forty per cent of people with mental health problems thought health and social care services helped overcome isolation, but over two thirds did not have access to the services they felt they needed.

<sup>1</sup>See Appendix one for full questionnaire.

<sup>2</sup>See Appendix two for full details.

## Not alone? Isolation and mental distress

### The extent of isolation

Isolation causes mental health problems and stigma around mental health problems can make isolation worse. This self-reinforcing cycle condemns millions of people with mental health problems to a life of social segregation. This new survey from Mind indicates that 84 per cent of people with mental health problems feel isolated.

More worrying is that 80 per cent of respondents from this survey reported that isolation actually impedes their recovery from mental health problems. This new research confirms that people with mental health problems are among the most isolated in society. This figure dwarfs the general public's experience of isolation, which comes in at just 29 per cent.

### Young people

Isolation, and the circle of stigma and arrested recovery that comes with it, was highest amongst the youngest respondents to the Mind survey. Of the 18 to 24 year olds surveyed by Mind, 92 per cent felt isolated (compared to 84 per cent of the general sample).

disengaged when services don't feel tailored to meet their needs. Preventative and stigma-busting work in schools is currently under-developed, lack of understanding from peers then contributes to an already vicious cycle of isolation for many young people.

This pattern was mirrored in the NOP survey, which also found that, at 35 per cent, adults between 15 and 24 were the most isolated age group (compared to 29 per cent overall).

"Isolation leaves me with only my own mind for company, and the thought of it spins around and around and I am unable to offload it to anyone. When I have been really sick, the thing I wanted most in the world was for someone to come and talk to me, so I could tell them what was going on and not have to suffer alone."<sup>3</sup>

Further, in Mind's survey, over three quarters of those aged 18 to 24 reported that isolation caused or contributed to their mental health problems. Almost 90 per cent of respondents aged 18 to 34 reported that isolation compromised their ability to recover or cope with their mental health problems.

"To be honest, I do not have any concrete ideas of what helps. I know that I go out with friends when they are around (but that can sometimes exacerbate matters!) and confide in my boyfriend who is very caring and understanding. Reading has been a great escape for me. The best thing I ever did, however, was psychotherapy."<sup>4</sup>

Specific mental health services for young people are often over-stretched and struggle to meet the ever-increasing need. Adult mental health services are designed to care for the full age spectrum and young people often feel

### Route 97, Northampton and District Mind

Route 97 is a Northampton and District Mind service for young people aged 16 to 25 years old. The service is aimed at young people who have either a severe and enduring mental health problem or more common mental health problems with complex additional needs. Route 97 has been particularly helpful to young people who have been defined by other services as difficult to engage or for those requiring multi-agency support or who have a history of dysfunctional family life or chaotic lifestyle, who as a result are more likely to feel isolated and disengaged from society.

The service user decides on the content, purpose and frequency of the contact between Route 97, themselves and other agencies, and therein lies its success. The project is very much person centred, working to the individual's agenda and pace and so support packages are tailored according to what each young person finds helpful.

This might include practical support with official forms or accessing benefits or housing. For other young people, Route 97 might help them towards more independent living through budgeting, shopping or even menu planning.

Some users find that one-to-one support is most helpful, and the project can provide encouragement with exploration and understanding of emotions, help to deal with self-harm or attempts at suicide or anger management.

The project also offers advocacy to support the individual at mental health reviews, benefits rulings, or help to deal with solicitors or the courts.

The philosophy of the project is to be user focused and needs led. And its success with young people, who otherwise would be isolated within their community, comes down to recognition by young people involved with the project that it is their service, and that it works independently from other statutory services or agencies.

<sup>3</sup> Mind survey respondent, female, 18 to 24. White British.

<sup>4</sup> Mind survey respondent, female, 18 to 24, White British.

## Not alone? Isolation and mental distress

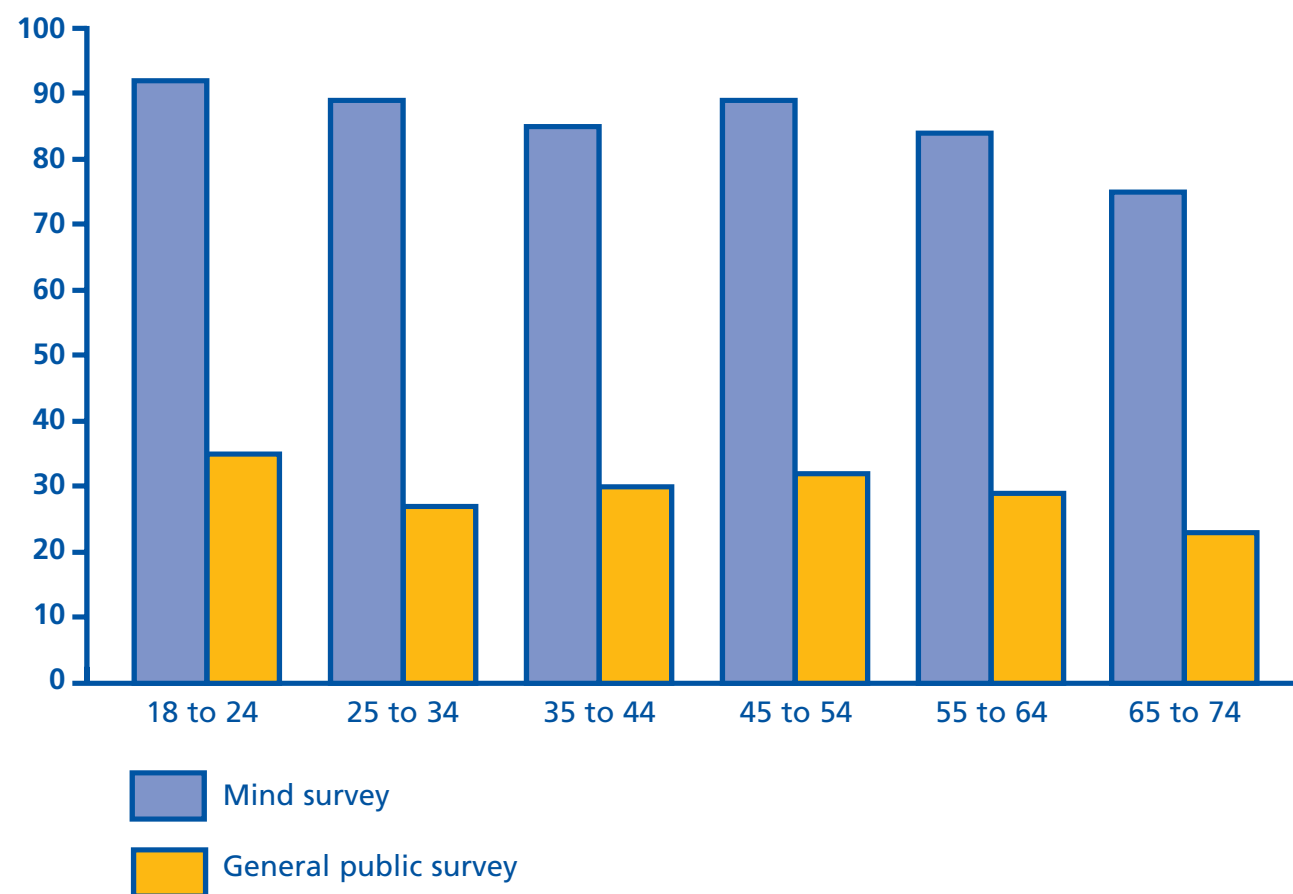
### Older people

At the other end of the age spectrum, in the Mind survey, respondents aged 65 and over were the least likely to have had experience of isolation (75 per cent).

Again, although less prevalent, similar patterns of isolation amongst the older populations were reflected in the NOP poll. Here, again, of all age

groups, the lowest rates of isolation were reported by people aged over 65 (23 per cent). This is an interesting result and may indicate that some of the most isolated older people are beyond the reach of Mind or other networks. According to the NOP survey, the vast majority of people (70 per cent) see older people as the most isolated group in society.

### Reported rates of isolation



Relationship issues featured prominently in the findings of both surveys. Human contact is intrinsically linked to inclusivity and enjoying a close relationship is a crucial component in avoiding isolation. In the Mind survey, lack of close relationships (71 per cent) and difficulties around relationships (74 per cent) figured highly as causes of isolation. Within the general public too, lack of relationships seem to have a direct impact on isolation. Single (36 per cent), divorced, separated or widowed counterparts

(37 per cent) were considerably less isolated than married people (24 per cent).

But there are other groups caught in the isolation trap. Ninety per cent of people with experience of mental distress in rural areas felt isolated, and almost 90 per cent of respondents from Black and minority ethnic communities also reported isolation. Over two thirds of the latter group identified isolation as a major cause or contributory factor to mental health difficulties.

### Causes of isolation

What are the causes of isolation for you?	Major cause Per cent	Contributory cause Per cent	Not a cause for you Per cent
Lack of understanding by others about mental health issues	47	30	8
Discrimination on mental health grounds	24	34	23
Discrimination on other grounds (for example, racism, sexism, homophobia, disability, ageism)	16	22	38
Isolating effects of mental distress (for example, fear, withdrawal)	54	25	5
Lack of confidence because of mental health problems	53	25	5
Difficulties around relationships because of mental health problems	48	26	9
Lack of close relationships	45	26	13
Lack of work	28	26	26
Lack of money	30	29	24
Lack of transport	19	23	36
Poor housing	19	23	36
Lack of information about community activities and/or services	17	26	36
Lack of support services	27	30	23
Lack of places that feel safe	33	27	20
Other	11	4	0

Note: Percentages do not add up to 100 per cent, as some respondents did not answer this question.

## Not alone? Isolation and mental distress

### Mental health, stigma and discrimination

It is important to recognise that the symptoms of mental distress contribute greatly to the causes of isolation. Mind's survey found that 79 per cent of respondents felt that mental distress itself contributed to their isolation and 78 per cent reported lack of confidence due to mental health problems as a factor. But whilst this is clearly an important piece of the jigsaw, it is by no means the only one.

Society's stigmatisation of mental health must be seen as a central cause of isolation in this group. People with experience of mental distress are keenly aware of this stigma. Three quarters of respondents from the Mind survey say a major cause of their isolation is the lack of understanding by others about mental health issues.

In the 1996 report *Not just sticks and stones*, 45 per cent of respondents, all with current or past experience of mental distress felt that discrimination had increased in the preceding five years. Half felt unfairly treated by general health care services. Almost half had been abused or harassed in public and a quarter felt at risk of attack inside their own homes.<sup>5</sup> Eight years later, Mind's most recent survey finds debilitating discrimination and stigma still affects people experiencing mental distress. Fifty-eight per cent of respondents said that isolation was linked to discrimination relating to their mental health.

"I find I'm isolated because of people's reaction to me having a mental health problem. I get mocked, pushed and stared at, so feel isolated and I can't go out much or make friends, so I get more depressed as a result."<sup>6</sup>

In 2004, the British journal of psychiatry identified that a characteristic feature of stigma

for people with mental health problems is fear of disclosing their mental health status.<sup>7</sup> These fears are well founded. In 2000, Depression Alliance discovered that 23 per cent of the general public thought people with a diagnosis of depression would not eventually recover while the same proportion thought people with a diagnosis of depression were a danger to others.

In their 2000 survey, the British Psychological Society found that a quarter of mental health service users felt at risk in their own homes and 26 per cent had been forced to move because of harassment.<sup>8</sup> In the same year, 66 per cent of respondents to a Mental Health Foundation survey said that the risk of discrimination and stigma would prevent them from telling some people about their experience of mental distress.<sup>9</sup> For many people, the most common discrimination was from those closest to them, family and friends.<sup>10</sup> In 2001, 62 per cent of all respondents to a Mind survey, who stated that they felt recovered or were coping, said the main barrier to recovery was the attitude of the general public.<sup>11</sup> In the current survey, 58 per cent of all respondents found that discrimination on mental health grounds was a factor in the isolation they experienced, with 80 per cent of Black and minority ethnic respondents citing this as a factor.

"I didn't say anything to my family 'cause I thought they would be appalled actually."<sup>12</sup>

"My neighbours have at times called me a 'lunatic' or 'insane' because I used to see a psychiatrist. I realise they're too stupid to understand so I ignore them. I've tried to explain but it's useless. They even tried to get a petition together to have me moved!"<sup>13</sup>

"Feeling scared that I will be judged because of my mental health problems has resulted in me avoiding social contact. Social contact would make me feel more normal and in touch. I feel unable to seek out social contacts."<sup>14</sup>

Thirty-eight per cent of respondents reported that they also experienced other forms of discrimination that increased isolation, a figure that jumped to 61 per cent for Black and minority ethnic groups. The double discrimination experienced by people with mental health problems from Black and minority ethnic communities has been well reported elsewhere.<sup>15</sup> For this group, racial discrimination

### Social exclusion

Poverty, in every sense, has a massive impact. Lack of transport and poor housing were seen as major or contributory causes of isolation by over a third of people with mental health problems.

Lack of money was an additional isolating factor for 59 per cent of respondents with experience of mental distress. For Black and minority ethnic respondents, this was even more likely to be a problem, with 65 per cent of the sample mentioning it.

prevalent within society is compounded by stigma associated with mental health difficulties, making social exclusion more acute.

The stigma and discrimination that individuals know they may face when they disclose a mental health problem can make it more difficult for people to seek help and so, in itself, can make it harder for people to start the road to recovery.

It is clearly the case that the attitudes of the general public towards people with mental health difficulties cause great distress. But this is not the whole picture.

"Lack of work, money and transport intensify the very real aspect of social isolation and environmental or clinical depression."<sup>16</sup>

"Within mental health, which is poverty related, I have been in poor housing and low benefits, this creates an isolation in itself and separates you from the community, this makes you feel rejected by people and made to feel different."<sup>17</sup>

<sup>5</sup> Read J. and Baker S. 1996, *Not just sticks and stones: a survey of the discrimination experienced by people with mental health issues*, Mind, London.

<sup>6</sup> Mind survey respondent: female, 24 to 34, White British.

<sup>7</sup> Dinos S. et al. February 2004, 'Stigma: the feelings and experiences of 46 people with mental illness' *British Journal of Psychiatry*.

<sup>8</sup> *Recent advances in understanding mental illness and psychotic experiences*, June 2000, The British Psychological Society, p.53.

<sup>9</sup> *Pull yourself together*, 2000, The Mental Health Foundation, London, p.11.

<sup>10</sup> *Pull yourself together*, 2000, The Mental Health Foundation, London, p.16.

<sup>11</sup> Baker S. and Strong S. 2001, *Roads to recovery*, Mind, London.

<sup>12</sup> Survey respondent: female, White British in Dinos S. et al. February 2004, 'Stigma: the feelings and experiences of 46 people with mental illness', *British Journal of Psychiatry survey*.

<sup>13</sup> Mind survey respondent: female, 45 to 54, White British.

<sup>14</sup> Mind survey respondent: female, 45 to 54, White British.

<sup>15</sup> *Breaking the circles of fear*, 2002, Sainsbury Centre for Mental Health

<sup>16</sup> Mind survey respondent: male, 45 to 54, White British.

<sup>17</sup> Mind survey respondent: male, 33 to 44, Black or Black British.

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### Overcoming isolation

#### Help to overcome isolation (all respondents)

What do you find helpful, or would you find helpful, in overcoming isolation?	This helps or helped Per cent	This would probably help if it were available to you Per cent
Support to make friends and contacts	47	27
Support to go out	38	31
Support to take part in social or recreational activities	38	34
Support to take part in faith or religious activities	23	20
Financial support for social, leisure, recreational activities	30	33
Financial support for other reasons	15	23
Ready use of telephone	55	11
Ready use of internet	34	21
Information about community activities and services	34	24
Day services	35	21
Self-help groups	33	30
Befriending	18	34
Mentoring	13	30
Local mental health organisation	40	22
Involvement in campaigning for better mental health	32	23
Affordable social activities	27	32
Friendly, welcoming social activities	35	34
Social activities that are easy to get to	26	36
Other	7	8

### Human contact

What the general public and respondents to Mind's survey agree on is the factors most likely to overcome isolation. Beyond societal causes like the stigma and discrimination experienced by people with mental health problems, there is one factor above all others that repeatedly emerged as a key factor in beating isolation – the ability to form relationships and to engage with other people.

In both the Mind survey and the NOP poll of the general public, social support, friendship and relationships materialised as crucial combatants to isolation. In Mind's survey of mental health service users, support to make friends, accessible, affordable social activities and access to mental health organisations, day centres or befrienders all scored highly as helpful or desirable means to overcoming isolation.

The NOP survey respondents felt making new friends (49 per cent) and joining a club or

social group (36 per cent) were the most likely activities to help overcome isolation. But this apparently obvious solution is, for some people with mental health difficulties, a daunting and even impossible prospect. While three quarters of the 2004 Mind survey respondents identified the importance of friends and contacts, they also identified the need for support in making or keeping these.

Several people lost friends or were excluded by their families as a result of their mental health problems. Lack of understanding on the part of family and friends was a strong theme running through responses to Mind's survey. This can reinforce isolation as people feel hurt, exclude themselves or put on a front. The risk of confiding can be too great, and fear of rejection and others' judgement and difficulty expressing feelings all work against relationship.

#### Hartlepool Mind, Mental Health Support Network

Hartlepool Mind's Mental Health Support Network offers a range of services for people with mental health problems, designed to give isolated people the confidence and skills to re-integrate into the community. Referrals are either voluntary or made through GPs, psychiatrists or other agencies. Clients are offered a range of short workshops designed to grow people's life skills and work on relationship building and making social networks. However, the charity recognises that the key to successfully overcoming isolation is to integrate clients fully back into the real world.

Hartlepool Mind draws on existing community resources and has built up over 90 links with the local community. People are encouraged and supported to improve key skills like financial planning and IT training, and practical help is given with housing and benefits. Many also find work volunteering in local organisations. This is viewed as a useful way of re-entering and feeling valued within society. Socially, help is given to join groups and clubs, from exercise classes to arts and crafts to local college courses.

"Very effective in relieving the stress for a particular problem. The problem has now ceased to exist."  
 "It has given me my life back."  
 "It was good, even got me back to work."  
 "Very good and helped me a lot."

### Mind in Dacorum befriending project

Mind in Dacorum operates a befriending project that offers support, not just through the human contact of a befriender but also online support through the internet. Befrienders spend on average one to two hours a week with individuals and offer social support on a range of activities. These might include going shopping together, going to the cinema, meeting up in cafes, taking up a hobby together or even just a listening ear over a cup of tea at the person's home.

People are referred through the Community Mental Health Team or other agencies. Workers from the Mind project then meet the person in their home to establish their needs and to build up a profile of their hobbies and interests in order to match them to a suitable befriending volunteer. While individuals are on the waiting list for a befriender, Mind in Dacorum offers them a weekly telephone befriending service and access to the group's internet befriending. Here, individuals can access the organisation's chat rooms and message boards and thus have immediate access to befriending support. Group support is also offered if a number of people with similar interests are identified.

Suitable befriending volunteers are given intensive mental health training initially, backed up with ongoing support and information sessions on various aspects of mental health. Befrienders are offered additional training towards a certificate in counselling skills as an added incentive. The matching process is carefully planned and regularly evaluated and both parties have access to staff at Mind in Dacorum for additional support at any time.

"I really look forward to seeing my befriender each week. We sit and talk – she listens to my worries and reassures me."

"I rarely go out and often feel very lonely. My befriender takes me into town and we try out different coffee shops – her visit really brightens my week."

and could, potentially, be used to purchase telephone and internet services as a direct mechanism of support.

The type of services that service users can access via direct payments schemes are much more varied than what was previously on offer to this client group.

Mechanisms for delivering social support to people who are isolated through mental distress, rather than other disabilities, are extremely under-developed. Historically, there has been an emphasis on psychiatric-led community mental health services in which social care has been formulated and delivered to a medical model of support. In addition, local authority social services departments have preferred, for

budgetary reasons, to leave the social care of mental health clients within the NHS.

The mainstream social care system, provided by local councils, is often inaccessible and little used by people with mental health problems. This can be explained by a tradition in social care for mental health where only those with serious mental illness are provided with support in the community. This is usually only based on therapeutic need. People who could benefit from a modest background of support to help them gain confidence and maintain crucial links with the wider society are often refused an assessment for services because they are not patients receiving consultant care under the Care Programme Approach (CPA) or, in some areas, enhanced CPA.

### Tools of communication

Overcoming isolation doesn't always have to entail formal support groups or societal change. Surprisingly, the single greatest asset in overcoming isolation, identified by respondents to the Mind survey, was ready access to a telephone (55 per cent). However, one in ten respondents who indicated that they would find this helpful did not have it, rising to one in five of the respondents from Black and minority ethnic communities. Ready use of the internet was also identified by many people as beneficial, particularly amongst younger people (72 per cent found it useful or would if they had access to it). However, there were still over one in five respondents without online access who felt they would potentially benefit.

Access to a telephone clearly has great potential for maintaining links with community and social and emotional networks. Social services can already provide computers, adaptations and software for people with sensory disabilities to enable them to communicate. It is not inconceivable that communications equipment could be provided for those identified as lacking this facility and who could be recognised as having a clear need.

Anyone with a community care assessment of need is entitled to be considered for a direct payment of cash to purchase services rather than accepting services commissioned and/or delivered by social services. This could lead to a revolution in the accessibility of support for social isolation



### Eastleigh and District Mind Mind-IT project

The Mind-IT project has been running for over 10 years to provide quality training and access to IT for local people with mental health problems. The project is flexible and caters for individual needs, whether it is training towards recognised qualifications, support to work on their own projects like writing poetry or creating greeting cards, or time to surf the internet and email contacts and friends. The project aims to achieve all this in an environment that is non-pressurised and confidence building and where social interaction is enhanced so those students are enabled to take a fuller part in the community.

Mind-IT even has a project that takes laptops out to hospital wards so that inpatients can receive IT training and use the internet. The wireless outreach network goes into hospitals and day centres, helping people to gain skills and confidence with a view to moving to a Mind-IT class or mainstream education later on. Since this project was launched in May 2003, nearly 300 people have accessed the service.

Over the years, the project has evolved and has now moved to bigger premises and established links with local colleges and social services, which enables it to provide a range of recognised IT qualifications. The following statistics speak for the scheme's success over the last decade:

- Thirty-three people have returned to full-paid work.
- Eleven students left to return to education.
- Fifty-one qualifications have been gained by Mind-IT students.
- One student started her own barge painting business.
- One student has started a jam-making and buffet business.
- One student has become a qualified IT tutor.
- One student went on to study for a degree in computer science.

This year, Mind-IT went on the move to Mind's Annual Conference 2004 in Harrogate, where, for the second year running, they provided cyber café facilities for delegates. The project will shortly be starting to run small classes in a local library to help people use facilities in their community.

"Mind-IT has been invaluable to me in terms of confidence building and enabling me to access a mainstream college. The tutors are excellent, both in their subject knowledge and their ability to make students feel that they can achieve considerably more than they perhaps realise. This is all done in an environment where people are not put under any pressure, in my opinion a very clever juggling act."

### The role of health and social services

Over 40 per cent of all respondents found that health and social services helped them in overcoming isolation. Of the services which respondents felt helped them make social contact and feel part of the wider community, Community Mental Health Teams (CMHT) were found to be helpful by 27 per cent and day centres helped 28 per cent of respondents.

The particular benefits of mental health and other support services mentioned included not having to put on a front and having the companionship of others who understand mental health difficulties from their own experience. Some respondents spoke of having support within the mental health world and contrasted this with the wider community or society in general. Yet, at the same time, some respondents (15 per cent) reported that these services aggravated their feelings of isolation. They reported feeling isolated by not being understood by professionals, by being shut away in secure settings, being misdiagnosed, or by not having the impact of an additional physical impairment understood. Leaving hospital was a particularly vulnerable time. Moving from being among people to living alone and setting up life again with little or no support was found to be extremely isolating.

Over two thirds of respondents reported that, during the preceding two years, they had had to stop or been denied the use of a service they had, or would have, found helpful. A third of this group of respondents reported that the reasons given for this was because they were considered to be "better" or that their problems were not sufficiently severe. This reinforces anecdotal reports to Mind of services introducing inappropriately high service eligibility assessment criteria, which excludes all but the most severely ill. In 1999, the then Secretary of State for

Health, Frank Dobson promised "Mental health services and the professionals who provide them will get the attention and resources they deserve."<sup>18</sup> Mind's survey results suggest this simply isn't happening. The evidence is that attention and resources are not being directed towards those with less severe mental health problems despite their obvious need.

These findings seem to underline that a major barrier to accessing social support is the assessment process itself. Previous evaluations have identified an inability of care managers and social workers to assess appropriately. The assumption often being that assessment can only be service-led and that it is pointless to assess an individual for services that don't exist. However, there is also an issue to be addressed over assessors recognising the full breadth of need across all mental health problems. A better understanding of the scope of direct payment schemes is also needed. More broadly, moves must be made away from the existing culture of care, towards one of support enabling people with mental health problems ultimately to look after themselves.

<sup>18</sup> Department of Health 1999, *National service framework for mental health*, HMSO, London.

### Implementing direct payments in mental health: an evaluation<sup>19</sup>

This report focuses on an evaluation of the national pilot to implement direct payments, as a means to more independent living, in mental health across five local authority sites in England from February 2001 to July 2003. The Community Care (Direct Payments) Act came into force in 1997 and gave local authorities the power to offer direct payments to people assessed as eligible for community care services, including people with mental health problems. Despite pressure to increase implementation of direct payments nationally take-up by people with mental health needs has been slow, particularly compared to other eligible groups. In reality, most local authorities have done little to implement direct payments in mental health.

Evaluation of the pilot found that direct payments were being used for a variety of activities and tasks, including, social, personal and practical support, transport to enable access to voluntary work or social activities, educational support to pay for course fees and for leisure activities, such as gym membership or swimming classes.

The vast majority of respondents felt that direct payments had increased their independence, that they had more control over their life, and had had an overall positive impact on their mental health. The evaluation revealed that much work still needs to be done in terms of encouraging care coordinators to consider direct payments for clients with mental health needs. Professionals were found to be reluctant to offer direct payments for mental health and were often highly selective about who they considered eligible for the scheme.

The evaluation made specific recommendations in order to build on the national pilot, including:

- better promotion of the scheme through local authorities, National Institute for Mental Health England (NIMHE) and national guidance
- establishing steering groups in every local authority to support implementation of the scheme in mental health
- action to raise awareness of direct payments amongst mental health service users and practitioners.

The evaluation concluded that routine consideration of direct payments for people with mental health problems is still a long way off. It advocated positive action to ensure direct payments are offered as a route to achieving independent living and social inclusion for people with mental health needs.

Recipients often used direct payments to employ a PA to enable them to do everyday things. One recipient said of the scheme:

“There are some things that I couldn’t do, like go into busy shopping centres... and shop, although I would like to, but if I have got someone with me, then I will do it. I just don’t like to go to crowded places on my own. It’s not so much for the company, but I feel scared of what might happen to me, and I have quite a lot of panic attacks and agoraphobia as well. So I use it for shopping and to do a new course.”

For more information, contact HASCAS, 11-13 Cavendish Square, London W1G 0AN, tel 020 7307 2897.

### Government anti-stigma campaigns

In its 1999 report on social exclusion and mental health problems, Mind recommended that if the Government were to improve the nation’s mental health and challenge the stigma associated with mental health problems, it had to prioritise mental health.<sup>20</sup> Of the eight programmes to improve health in England published by the Government since 1999, the mental health programme was the first. Within that programme, the first priority identified was mental health promotion.<sup>21</sup> Alongside this, England has seen the establishment of the anti-stigma campaign Mind Out for Mental Health. The Welsh Assembly Government launched an equivalent mental health improvement programme in 2002, but has yet to initiate an anti-stigma campaign.

On first sight, this is encouraging. However, an examination of the figures suggests a less inspiring reality. One in four people in Britain

experience mental health problems. Yet while £4 million per year is spent on the See me anti-stigma campaign in Scotland with a population of just 5 million people, Mind Out for Mental Health sets the Westminster Government back just under £1 million a year for an English population of around 50 million. This means the Scottish Executive spends 40 times more per person than is spent on the English anti-stigma campaign. And, as mentioned above, there has to date, been no specific national investment in anti-stigma work in Wales.

A full five years after the launch of its mental health programme, Government is failing in its commitment to promote mental health, both in terms of the promotion of individuals’ mental health and in challenging the stigma attached to people with mental health difficulties.

### Conclusions

Mind’s survey findings suggest a strong link between the isolation experienced by people with mental health difficulties, the detrimental effect this has on mental health and the isolating effects of society’s prejudice towards, and lack of understanding about, mental health issues. For the great majority of the Mind survey respondents, being isolated caused or contributed to their mental distress and restricted recovery from and/or coping with their mental health problems. Poverty and racial discrimination were factors likely to increase this isolation enormously.

If Government is to be true to the laudable aims of promoting good mental health and fighting mental health discrimination, it needs to acknowledge the links between isolation, stigma,

poverty, discrimination and mental health. It must take on board that effective promotion of good mental health requires a vastly enhanced anti-stigma campaign. Government cannot shy away from the fact that this will cost money, but money is not the sole answer. If people with mental distress are to be truly and fully integrated into society, there must be a fundamental shift in societal attitudes towards people experiencing mental distress. The first step to achieving this must be taken by Government. To fulfil its promise to people with mental health difficulties, Government must devote not only sufficient financial resources but also political will to fighting prejudice and supporting individuals with the health and social services that contribute most to recovery.

<sup>19</sup> Spandler H. and Vick N. 2004 *Implementing direct payments in mental health: an evaluation* HASCAS, London.

<sup>20</sup> Dunn S. 1999, *Creating accepting communities*, Mind, London.

<sup>21</sup> Department of Health 1999, *National service framework for mental health*, HMSO, London.

## Not alone? Isolation and mental distress

### Recommendations

#### Government

- Government must increase its commitment to anti-stigma activities in England and Wales, particularly among young people and in schools, to counteract the discrimination faced by people with mental health problems and to promote social inclusion.

#### Department of Health

- To develop better mental health services for young people.
- To make social inclusion a central element of both health and social care assessment protocols so that individuals' care packages maximise opportunities for social inclusion.
- To amend social care guidance to ensure telephones, access to the internet and other low cost, high impact ways of minimising isolation are provided for people with mental health difficulties where appropriate.
- To promote and extend direct payment schemes for mental health problems to enable greater flexibility and accessibility to social support to counter isolation.
- To encourage primary care services and individual GPs to develop links with local leisure, education and voluntary services, and to ensure prescribing practice addresses social isolation.
- To ensure wide access to health and social care services, which offer opportunities for social interaction and development of social skills and especially to informal activities such as drop-ins.

#### Public services, including transport, housing, the benefits system, employment services, the police force, leisure services and health and social services.

- To audit the provision of their services to identify and eliminate systemic discrimination against people with mental health difficulties.
- To introduce proactive initiatives to ensure that this group can gain full access to services and so participate fully.
- To employ people with experience of mental distress in the training of front line staff and in planning services to ensure that services fully meet needs.



## For better mental health

### Appendix one

## Mind survey on isolation

The theme of Mind week 2004 is isolation. This survey is to help us draw attention to the isolation experienced by people with mental health problems and to campaign for change. We need current feedback from people who experience mental distress, and/or have recent experience of mental health services, to make sure that we are asking for the right things and have the evidence to support this. Please take part if you can, and fill in as much of the questionnaire as you want or are able.

Isolation might be feeling cut off from other people or not having as much contact as you would like, or being left out of family and other relationships, social life and recreation, or work (paid or unpaid).

Please tell us about your current or recent experience (unless stated otherwise, over the last five years).

The information you provide will be treated in confidence and destroyed after the end of the project. You do not have to give your name.

However, we should like to use anonymous quotes from people's responses in the survey report, as this will convey the reality of the situation. We shall do this in a way that does not identify individuals.

- Please tick if you do not want us to use any direct quotes from your response.
- Please tick and provide contact details below if you might be interested in doing media interviews (these can be anonymous).
- Please tick and provide your name and address (email or postal) if you would like a copy of the survey report. The report will be available in Mind Week (15 to 22 May 2004) and will be distributed around Mind's networks, so it will be easy to get one, if you prefer not to give your contact details.

If you would like to give your name and contact details, please do so:

.....  
.....

Please send your completed questionnaire to:  
Mind (MW survey), FREEPOST (WD2336), London E15 4BR (no stamp required) by 16 February 2004.

Many thanks  
Sophie Corlett  
Policy Director

## 1. Experience of isolation

Do you have current or recent experience of isolation that relates in some way to your mental distress?

Yes  No (If No, please go to question 6)

## 2. The effects of isolation

Does (or did) isolation cause or contribute to your mental health problems?

Yes, it is (or was) a major cause of my mental health problems  
 Yes, it is (or was) a contributory cause of my mental health problems  
 No, it is (or was) not a cause of my mental health problems

Please tell us more.

Does (or did) isolation make it harder for you to recover from, or cope with, mental health problems?

Yes, it makes (or made) it much harder  
 Yes, it makes (or made) it somewhat harder  
 No, it does (or did) not make it harder

Please tell us more.

## 3. Causes of isolation

What are the causes of this isolation for you? We realise that many of these causes will have an effect on each other. Please tick the appropriate box for each.

	Major cause	Contributory cause	Not a cause for you
<b>Attitudes, awareness and discrimination:</b>			
Lack of understanding by others about mental health issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discrimination on mental health grounds	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discrimination on other grounds (eg racism, sexism, homophobia, disability, ageism)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Personal factors relating to mental health:</b>			
Isolating effects of mental distress (eg fear, withdrawal)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of confidence because of mental health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulties around relationships because of mental health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Circumstances:

	Major cause	Contributory cause	Not a cause for you
Lack of close relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of information about community activities and/or service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of places that feel safe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other – please state	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us more about your experiences, (eg, the circumstances of the discrimination, what lies behind the lack of work/money/transport and so on).

## 4. Overcoming isolation

This question is about:

- what you find helpful in overcoming isolation, and/or
- what you think you would find helpful in overcoming isolation if it were available to you.

For each one that you consider to be important to you in overcoming isolation, please tick the appropriate box.

	This helps (or helped)	This would probably help, if it were available to you
<b>Support (from other people):</b>		
Support to make friends and contacts	<input type="checkbox"/>	<input type="checkbox"/>
Support to go out	<input type="checkbox"/>	<input type="checkbox"/>
Support to take part in social, leisure, recreational activities	<input type="checkbox"/>	<input type="checkbox"/>
Support to take part in faith/religious activities	<input type="checkbox"/>	<input type="checkbox"/>
<b>Financial support:</b>		
Financial support for social, leisure, recreational activities	<input type="checkbox"/>	<input type="checkbox"/>
Financial support for other reasons (please say what)	<input type="checkbox"/>	<input type="checkbox"/>
<b>Communication:</b>		
Ready use of telephone	<input type="checkbox"/>	<input type="checkbox"/>
Ready use of internet	<input type="checkbox"/>	<input type="checkbox"/>

**Information, activities and services:**

- Information about community activities and services
- Day services
- Self-help groups
- Befriending
- Mentoring
- Local mental health organisation
- Involvement in campaigning for better mental health
- Affordable social activities
- Friendly, welcoming social activities
- Social activities that are easy to get to
- Other – please state

**This helps (or helped)**      **This would probably help, if it were available to you**

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

Please tell us more about what you do – or would – find helpful.

**5. Health and social services and overcoming isolation**

Overall, would you say that the health and social services you use (eg, community mental health team, day centre, or support workers):

- Help overcome isolation
- Make isolation worse
- Are not relevant to isolation

Do any of the following services, help you make social contact and feel part of the wider community?

Type of service	Yes	No	Don't know	You do not receive this service
Community mental health team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Residential home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supported housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us more.

**6. Access to services**

In the last two years, have you had to stop using a service you wanted to carry on using, or been denied a service?

- Yes       No

If yes, please say which service(s):

Was the reason that:

- They said you were better (or your problems were assessed to be less severe)
- The service closed
- The rules on who could use the service changed
- You could not afford the charges
- It was offered for a limited period
- It was too hard to get to

Another reason (please say what)

**7. Other thoughts on isolation**

Please tell us anything else about your experience of isolation, and what can be done to help overcome it.

**Basic information about you**

I am  male       female (Please tick)

Please tick your age group:

- Under 18       18 to 25       26 to 35       36 to 45       46 to 55
- 56 to 65       66 to 75       76 to 85       86 and over

Please tick your ethnic group:

- Black or Black British       Asian or Asian British
- Chinese       White British
- White Irish       Other White
- Mixed heritage       Other ethnic group (please state)

Please tick the type of area you live in:

- Rural       Small town       Large town or city       Other, please state

## Not alone? Isolation and mental distress

### Appendix two

#### The NOP public opinion survey

##### Question one

Have you ever felt isolated?

- Yes
- No
- Don't know
- Refused

##### Question two

Even if you have never felt isolated, what do you think are the THREE main reasons people can feel isolated? The following options were not shown to respondents.

- Lack of close relationships
- Lack of work
- Lack of money/no money
- Lack of transport/no transport
- Poor housing
- Mental health problems
- Racism
- Sexism
- Lack of support services
- Ageism
- Homophobia
- Physical health difficulties
- Bereavement
- Other (specify)
- Don't know

##### Question three

If someone were feeling isolated, what THREE things do you think would help them overcome their feelings? Options were not shown to respondents.

- Make new friends
- Join a club of social group
- Faith or religious activities
- Become a volunteer
- Try to get a job
- Access to more money/better finances
- Improved housing
- Better transport
- Access to a telephone
- Access to the internet
- Support group
- Affordable social/leisure activities and/or facilities
- Social/leisure activities
- Other (specify)
- Don't know

##### Question four

Thinking about different groups of people in our society today, looking at this card, can you tell me which THREE of these groups of people, if any, you think feel the most isolated in our society today? Just give me the letter next to each answer you think applies.

- Old people
- People with mental health problems
- People with physical health problems
- People with hearing or sight loss
- Asylum seekers
- Ex-offenders
- Bereaved people
- Students
- Homeless people
- People with poor health in general
- Executives
- Celebrities
- Other answer (specify)
- None of these
- Don't know

For details of your nearest Mind association and of local services, contact Mind's helpline, **MindinfoLine** on 0845 7660 163, Monday to Friday 9.15am to 5.15pm. Speech impaired or Deaf enquirers can contact us on the same number (if you are using BT Textdirect, add the prefix 18001). For interpretation, **MindinfoLine** has access 100 languages via Language Line.



**For better  
mental health**

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