

# rethink



## breaking the silence

creating a civil rights  
movement in mental health



# About Rethink

Rethink, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life. We provide hope and empowerment through effective services and support to all those who need us, and campaign for change through greater awareness and understanding.

## Contents

Introduction	3
What is a civil rights movement?	4
How do we create a civil rights movement in mental health?	7
- visibility	7
- mass appeal	10
Conclusion	12

# Introduction

In twenty first-century Britain, millions of people are forced to live as second class citizens. While we have taken great strides in recognising the rights of women and people who are gay or black, people with severe mental illness have been left behind.

People with physical disabilities now expect and demand to be included in all parts of society: in the workplace, in public debate, in public housing, on public transport. Legislation even requires positive action by public bodies to ensure that this happens. But far from receiving positive treatment, people with severe mental illness are kept out, sometimes deliberately.

People from the gay community, from black and minority ethnic communities, and people with physical disabilities have positive role models. There are positive stories in the media, sympathetic role models in soaps. We have women MPs, disabled MPs, gay MPs, black and Muslim MPs; too few perhaps, but we don't have any national politicians who have publicly declared a mental illness.

Instead, people face media coverage that links mental illness and violence; friends and neighbours who regularly drop insults like 'psycho', 'nutter' and 'loon' into casual conversations; employers who admit that they don't want to employ people with mental illness; and legislation which explicitly excludes people with severe mental illness from the highest positions in our society.

**silence... sends a clear message that your constituency feels itself too weak, too confused or too afraid to merit respect**

Randy Shaw, the Activist's Handbook

At Rethink, we want to change this. We want to break down the wall of discrimination that people face by changing laws and policies at a national level. We want to change people's attitudes to mental illness and people's behaviour.

The good news is that it is possible. While the comparison between the status of people with severe mental illness and other minority groups is disheartening right now, the history of these other movements can inspire and guide us. Other groups have moved from the margins of society to the mainstream. We can do it too.

To achieve this, we need a multi-faceted approach that includes:

- social marketing campaigns that genuinely change people's attitudes and behaviour towards mental illness
- policy change at national level to remove discriminatory barriers in legislation and practice
- a real civil rights movement that places people with severe mental illness at the heart of public debate.

This report is part of a series of reports looking at discrimination and stigma. It focuses on the last of these three: how do we learn from previous civil rights movements and apply these lessons to severe mental illness?

This report has been produced as part of Rethink Civil Rights, a three-year project aiming to campaign for all the rights of people with mental illness and funded by Comic Relief.

## Note

Part of this report is based on survey data from Rethink's Your Shout survey, which was disseminated in two different versions in England and Northern Ireland for a 4 month period (May-August 2007). The following figures are for respondents who stated that they had a mental health problem.

	Number
England paper questionnaire	804
England online questionnaire	111
Northern Ireland paper questionnaire	113
Northern Ireland online questionnaire	8
<b>Total</b>	<b>1036</b>

**Figure 1: Table showing the response rates to the paper and online versions of the Your Shout survey in England and Northern Ireland.**

## Demographic profile of respondents:

**Gender:** Male = 53%, and female = 46%.

**Age ranges:** The majority of respondents were aged between 35 and 54 years old. Those with the least responses were between 18 – 24yrs and over 75 yrs.

**Ethnicity:** 85% of respondents were White British, but of the other ethnic groups, the largest was the White Irish group. Only 3 other groups had over 1% respondents: White other and Black or Black British Caribbean group.

**Religion:** A question on religion was only included in the Northern Ireland questionnaire. The majority of Northern Ireland respondents indicated that they were Roman Catholic (33%) and Presbyterian Church in Northern Ireland (26%).

**Mental health experience:** The most frequently cited diagnosis of respondents were mood disorders (28%) and schizophrenia and other psychotic disorders (28%). A further 19% of respondents had more than one diagnosis. 15% of respondents did not cite a diagnosis.

## What is a civil rights movement?

### Human and civil rights are often used terms, but what do they really mean?

The United Nations defines human rights as those which are inherent in our nature and without which we cannot live as human beings. Human rights are about protecting our basic needs as human beings, which we all share simply by virtue of our humanity.

Civil rights can seem more abstract, but they are simply positive rights that enable us to lead a fulfilling life within a community or nation. They belong to us as citizens of a state, rather than as humans.

Jenny Morris contrasts the right of disabled people to have a child, a human right, with the right of disabled people to sit with the rest of their family in a cinema, a civil right.<sup>1</sup>

Civil rights can have another meaning. When we talk about 'civil rights', we often refer to historical civil rights movements that used activism, mass demonstrations, and mass media for the advancement of people's rights. Whilst they were controversial at the time, we now remember them as historic struggles for equality for women, Afro-Americans, disabled people and gay people.

How did these movements develop? What tactics did they use? And how can we learn from them to advance the rights of people with severe mental illness?

### Votes for women

One of the oldest examples of a civil rights movement is the women's movement which began in the UK with the fight against the Contagious Diseases Act 1864. This allowed the police to round up suspected prostitutes and subject them to forced examinations for signs of venereal disease. The struggle for the vote further galvanised women, and men, into action. Mass



participation activism, such as protest marches and demonstrations, publicity and lobbying, which was considered extreme in its time, combined to create the movement for change.

The sensationalist actions they used helped increase media interest, therefore spreading awareness of the cause even further. However, people participated in many different ways, including more traditional lobbying techniques. The huge numbers involved in this activism, and the clever use of marketing and lobbyists helped sway the government of the day enabling women to gain the vote. In 1918 women over 30 were given the vote and from March 1928, all adult women could vote.

#### Key learning points:

- range of participation opportunities
- participant actions with news value

### African American civil rights

The Afro-American civil rights movement reused many of the tactics used by the women's movement in the UK such as direct action and the use of media.



People stood up to fight racist laws, public and private acts of discrimination, poverty, and racial violence. "Direct action" such as bus boycotts, sit-ins, freedom rides, nonviolent resistance and civil disobedience continued from 1955 to 1965. One of the most famous actions was the Montgomery Bus Boycott of 1955-1956, led by Rosa Parks, Edgar Nixon and Martin Luther King.

The messages of the movement were communicated to an ever-increasing audience through a range of media. Freedom songs conveyed the passion of key activists who would not have been reached by traditional text-based communications. Bernice Johnson Reagon, a member of the 'Freedom Singers' remembered referring to the group as 'a

singing newspaper'.<sup>2</sup> The mass media ensured that images of civil rights workers, sit-ins, marches and inhumane treatment of African Americans were seen in every home in America.

#### Key learning points:

- simplifying messages
- using a range of media

## Gay rights

The gay rights movement has scored a major victory with the campaign for equal rights to civil partnerships. Public attitudes to the gay community have been transformed over the last two decades. Employers now promote themselves as wanting a diverse workforce, including people from the gay community. Events like 'Gay Pride' and direct action protest groups like 'Outrage' repositioned the gay community as a force to be reckoned with rather than a silent, excluded set of individuals.



The visibility of the community made corporations as well as public services sit up and take note, learning to see the community as an opportunity, not a problem.

We started to hear about the buying power of the 'pink pound'. Gay public figures, in the arts in particular, but increasingly in other sectors, helped further increase presence. This new presence formed the backdrop which allowed Stonewall to lobby Parliament to legislate for civil partnerships.

#### Key learning points:

- location of the problem
- media presence of role models

## Disability in America

The disability movement in the US began in the 1960s with the idea that people with disabilities are human beings with inalienable rights and these rights could only be secured through collective political action. Social prejudice, fear and shame had kept disabled children out of public schools. Disabled adults had been discriminated against in employment, housing, and public accommodation and were often incarcerated for life in state institutions and nursing homes. The disability rights and independent living movements are transforming US society and introducing new legislation to pave the way to a more equal society. The community advocacy model was influential and face to face contact with disabled people who had been trained in advocacy changed attitudes on Capitol Hill.

#### Key learning points:

- face-to-face contact
- training

## Workers rights

The Justice for Cleaners campaign has used direct action since 2006, with actions such as picketing outside the offices of major financial institutions and walk outs to make an impact on big businesses. Typically, cleaners in the City of London receive no sick pay, no pension, the legal minimum holiday allowance of 12 days a year plus bank holidays, and can earn as little as £5.35 per hour. Many cleaners have two jobs just to earn enough to make ends meet. The campaign argues for a living wage for cleaners, sick pay and holiday allowance. A similar campaign is now gathering momentum on the use of tips by restaurants to 'top up' wages below the statutory minimum. The campaign has reached out beyond the cleaners and used new media opportunities to spread their message.

#### Key learning points:

- use of new media

## Physical disability in the UK

The UK disability movement is strong, with national organisations such as the UK Disabled People’s Council, the Disability Alliance, RADAR and the Trade Union Disability Alliance. However it has not established itself in the public consciousness as the Afro-American civil rights movement and the women’s movement did and tends to be associated with physical disability rather than mental illness.

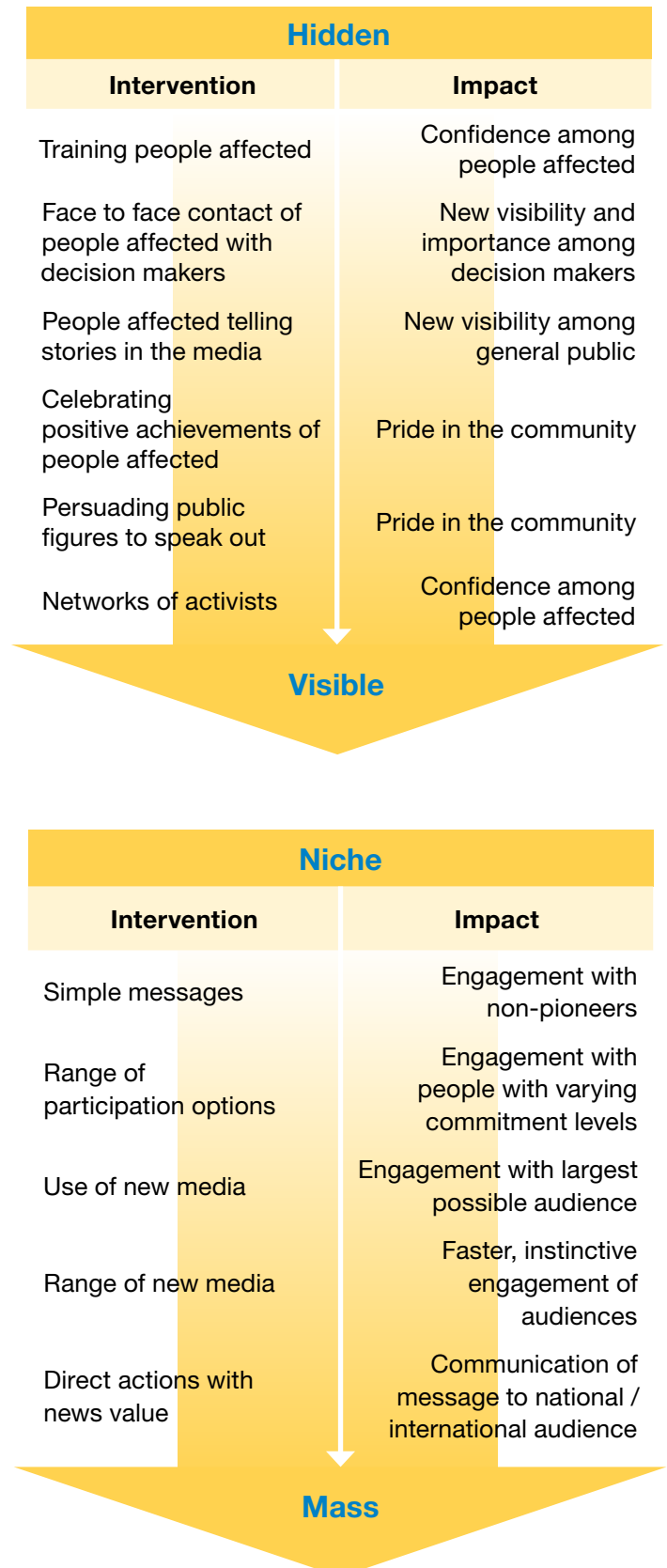
The US experience was used as a clear inspiration and provided hope, with the Disability Discrimination Act borrowing directly from the American concept of ‘reasonable accommodation’. The Disability Discrimination Act 2005 has forced the public to become more aware of physical disability issues. Physical adjustments to buildings, public transport and many workplaces are now considered standard rather than peculiarly good practice. Symbols of physical disability are now present in our daily lives, whether they are bendy buses, wheelchair ramps or white sticks, disabled MPs such as David Blunkett and Anne Begg. People with physical disabilities are speaking out and being counted rather than feeling that exclusion is inevitable and sitting back. Networks of disability activists have been created to allow people to learn from and be inspired by others’ successes.

### Key learning points:

- networks of activists

To achieve the ultimate aim of equality for people with severe mental illness, we must learn from these movements’ successes and practices. All have made a ‘hidden’ and silent community visible. All have enlisted the support of a wider group of people, rather than restricting it to people directly affected by the issue.

How do we achieve the same for mental illness in Britain in the twenty-first century? The two strategies go hand in hand: by making mental illness more visible, we will help to engage a wider group of people. We will look at each in turn.



# How do we create a civil rights movement in mental health?

## Visibility of the people affected

Mental illness is a hidden disability. Even if a friend has a mental illness, you may not know it. Even if a celebrity is experiencing a crisis, the headlines might not mention it. This invisibility leads us to underestimate the size of the community of people who experience it. It leads us to make assumptions about people who do have mental illness because our 'known' experience is so limited.

**So how do people with severe mental illness become visible?**

## Face-to-face contact

We can start with face-to-face contact. The social contact theory says that the best way to reduce discriminatory attitudes is through peer to peer contact. If you meet someone who looks like you, who talks like you, who lives near you and then find out that they have a mental illness, this shifts your attitudes and behaviour in a fundamental way.

**Rethink** will seek to involve people affected by severe mental illness in all meetings with decision-makers.

## Telling Ministers how it is

In 2008, Rethink supported 70 people affected by mental illness to come to Parliament and meet Lord Darzi to ensure that the community's voice was heard and influenced the NHS Next Stage Review.

Lord Darzi spoke to and listened to people's experiences and three key priorities were identified for the review.



Since 2000, Rethink has worked collaboratively with the Institute of Psychiatry, King's College London to deliver anti-discrimination training to professional audiences. People with experience of mental illness deliver the training alongside Rethink staff.

We have trained thousands of professionals in this way, including medical students, trainee psychiatrists, police officers, school nurses, college tutors, housing officers and citizen advice bureau staff.

We are now extending our reach as part of the Time to Change programme to pilot delivery to trainee teachers across four teacher training colleges/universities in England. Eventually, we would like all public servants such as GPs, Jobcentre Plus employees, duty solicitors, judges and benefits assessors to have this training, as well as large employers.

**time to change**

let's end mental health discrimination

## Media presence of role models

Face-to-face contact will only ever reach so far. We cannot meet every single Briton and match them with a similar person with mental illness. We can, however, use the media to achieve contact, by making sure people directly affected are spokespeople for the cause and to relate personal stories. We can also encourage and support celebrities and public figures who 'come out' about mental illness.

**Rethink** will increase the number of people directly affected acting as spokespeople for the organisation, year on year.

### Rethink's media volunteers

Since 2002, Rethink has trained and supported people directly affected by severe mental illness to speak about experiences in the media. Last year, 37 people told their story in the media through Rethink's media team.

**Rethink** will work with celebrities and public figures as part of the Time to Change social marketing campaign to reduce discrimination among the general population.

## Training

To be visible, people need to feel confident in the identity they are projecting. After years of neglect and insult, people affected by severe mental illness often lack confidence to speak out. People with mental health conditions are more likely to cite confidence as a barrier to social participation than other groups.<sup>3</sup> We need to provide training and support to individuals and link individuals together to provide peer support. We need to get decision-makers talking and (crucially) listening to people affected by severe mental illness so that people know they can have a voice.

**Rethink** will train campaigners from regions across England to become champions of this movement.

## Networks of activists

As a result of years of oppression and neglect, people affected by severe mental illness can become cynical about the prospect of change. The last big campaign to unite the sector, the Mental Health Alliance, achieved significant changes to an unpopular Bill, but the fact that the Bill passed in

**time to change**

let's end mental health discrimination

Time to Change is England's most ambitious programme to end the discrimination faced by people who experience mental health problems, as well as improve the nation's wellbeing. Mental Health Media, Mind, and Rethink are leading this programme of 35 projects, funded with £18m from the Big Lottery Fund and Comic Relief and evaluated by the Institute of Psychiatry at King's College, London.

The programme is founded on an international evidence base, and has people with direct experience of mental health problems at its heart. Local community projects work alongside a national high-profile campaign, a mass participation physical activity week, legal test cases, training for student doctors and teachers, and a network of grassroots activists combating discrimination.

We aim to work in partnership with all sectors and communities in order to tackle a long lingering taboo and one of the greatest social injustices.

**Rethink** will work with celebrities and public figures as part of the Time to Change social marketing campaign to reduce discrimination among the general population.



some form inevitably resulted in some campaigners feeling jaded. The mental health cuts implemented in 2006-7 as a result of Payment by Results distorting local health economies and recent changes to day services have also made campaigners feel weary and powerless.

At the same time, there is a constituency of people who want to be involved in politics. 89% of respondents with mental illness to Rethink's Your Shout survey were registered to vote. 43.1% tended to agree with the statement that when people with experience of mental health problems get involved in politics, they really can change the way the country is run compared to 20.6% who tended to disagree.

We need to show people in a simple way how action as part of a collective can make a difference. We need clear-cut stories about how ordinary people have brought about changes in local communities, whether by campaigning for services in a new way or challenging local decisions and speaking out.

**Rethink** will gather evidence from our members about successful local campaigns and disseminate this through our website, events and mailings.

## Locating the problem

People in marginalised communities often experience life as a series of 'problems', from everyday issues such as access to services and bureaucracy of public services to managing limited incomes. Public services and corporations in turn can see the marginalised community as a series of 'problems' that organisations have to deal with. People from these communities are rarely seen as 'opportunities', but in fact are often referred to as being 'difficult', 'problematic' or 'hard to manage'. Mental illnesses are often referred to as 'mental health problems'.

All these factors can lead to people with mental illnesses being seen as a 'problem' or 'dilemma' or 'issue' for society. But to create a civil rights movement, we need to be clear: the problem is not people affected by severe mental illness; the



## Rethink Politics

Since 2007, Rethink has been training people affected by mental illness on how to get involved in politics, at national and local level.

So far, we have trained over 200 people and put people in touch with local politicians, who have attended events, been questioned and listened to the experiences of people affected by mental illness.

problem is how other people deal with us. The community can, in many ways, be proud of how individuals have coped with a discriminating and cruel society. It is society that should be ashamed and which needs to change.

**We need to learn from the 'pride' of the gay community and use a language and way of working which instils a sense of pride in people affected by severe mental illness. The language of "recovery" is a good foundation for us to build on.**

**Rethink** will continue to celebrate the achievements of people affected by severe mental illness and tell positive stories about people's recovery.

## Mass appeal

Mental illness as a cause is still of limited appeal. The drive for service user and carer involvement has been essential to increase visibility of people affected by mental illness in many public arenas. However, it has meant that as a sector, our communications have often been targeted at a limited group of people with experience of mental illness and hence high knowledge and awareness of mental illness.

On the cultural dynamics model, where people are either pioneers, prospectors or settlers (see figure 2), mental illness only registers with pioneer audiences. This is usual: pioneers usually start movements, prospectors organise it and up-scale it and settlers join in when it is safe to do so.

All civil rights movements, however, have enlisted the support of people outside the community directly affected. White people were essential to the fight against slavery in nineteenth-century Britain. Men fought alongside women for the vote. Straight people supported gay friends, colleagues and relatives to fight for equality.

So how do we move the mental health cause to have mass appeal? How do we engage a mass audience?

## Message simplification

We need to simplify our message. Most civil rights movements have a simple mantra of ‘equality – now’. People with different motivations and interests can interpret this in many different ways, but the rallying cry brings people together. There is no need to learn a lot of jargon to identify with this message. It can connect quickly and easily with different audiences, whether or not they have direct experience of mental illness. We need to create messages that make sense to pioneers, prospectors and settlers.

**Rethink** will invest time in creating simple campaign and media messages, that don’t require prior knowledge of mental illness and appeal across a range of personality types.

## Range of participation opportunities

If we manage to engage people on a wider scale with a simple message, the next question is: what can these people do to participate? As well as offering training and involvement opportunities to people directly affected, we need opportunities for people without experience of mental illness, who nevertheless connect with the issue. We need a range of options, from mass protests to online petitions or ecampaigns.

**Figure 2: Pioneer, prospector and settlers value modes**

	Pioneers	Prospectors	Settlers
<b>Needs</b>	Inner directed	Outer directed	Security driven
<b>Outlook</b>	Ethical, altruistic or global	Entrepreneurial, commercial	Socially conservative
<b>Motivated by</b>	Self actualisation ‘Interesting’ and new issues and ways of doing things	Symbols of success  Esteem of others	Safety Trusted, authoritative channels and rules Sense of belonging.
<b>Avoid</b>	Discipline	Social risk	Change

**Rethink** will create a range of opportunities for people without experience of mental illness to participate.

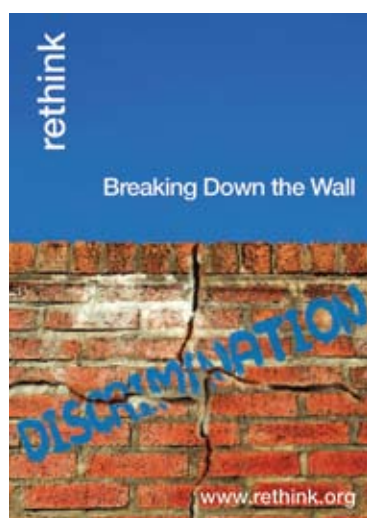
## Use of new media

Many civil rights movements relied on mass media to galvanise support. Communication is now more fragmented, with audiences split across a variety of traditional and new media, but the opportunities for the amateur communicator are far greater, with the use of blogs and message boards, than in the days of the all-powerful professional commentators. Message boards in particular offer the opportunity to challenge negative media coverage immediately.

**Rethink** will encourage our members to use online media such as blogs and message boards

## Range of media

To use these channels to our advantage, we need to communicate across a number of media. We need visual images that convey our message as well as words. Images are 'magic bullets' which slip under the consciousness of the audience.<sup>4</sup>



Whether through the stunts of the suffragettes, sit ins of the African American civil rights movement or Gay Pride marches, all movements have found ways to visually express their cause in powerful visual images.



**Rethink** will invest in images which convey campaign messages in a more direct way than words.

## Supporter actions with news value

The most obvious way to create images is through the actions of supporters. Iconic, colourful images need to be at the heart of actions to maximise its appeal to media outlets and therefore communicate with an even wider audience. To maximise the news value of actions, controversy needs to be at the heart of the action. From Rethink's previous work in Norwich, it appears that controversy can be courted without losing wider support and can generate national and international media coverage. These actions and the media interest they generate are often as important in effecting change as policy research.<sup>5</sup>

Rethink's use of a controversial statue of Winston Churchill as part of the Norwich anti-stigma pilot was accepted by most residents. The campaign is explored in more detail in the Breaking Prejudice report.

**Rethink** will invest in actions for a wide group of supporters to leverage media coverage and effect change.

## Conclusion

The mental health sector has much to learn from civil rights movements in other areas and other countries. Rethink will now apply these lessons to its campaigning work, by making the community visible.

### We will:

- increase face to face contact of people with severe mental illness with decision-makers and professional audiences
- work to place people with severe mental illness in the media as role models
- train up people in the community to increase confidence
- reduce 'lazy fatalism' through inspirational stories of other people with severe mental illness
- clearly locate the problem outside the community in our communications

### We will also seek to reach out to a wider audience than people directly affected through:

- simplifying our messages and using analogies with areas that a mass audience do understand
- giving the wider community a range of ways to join the movement
- taking advantage of new media
- communicating in a range of media
- inspiring supporter actions with news value

Rethink is now working to a civil rights agenda and hopes that other organisations, user and carer groups will support our work and follow this lead. This change of approach cannot be affected by one organisation or group alone. It takes a whole community.

The real question is: what will you do? How will you help to bring about a better world for people affected by severe mental illness?



**Sign up to join Rethink's  
civil rights campaigning at  
[www.rethink.org/campaignwithus](http://www.rethink.org/campaignwithus)  
or phone the campaigns team  
on 0845 456 0455.**

# Join us

Rethink works tirelessly to improve the lives of those affected by severe mental illness. If we are going to continue to succeed we'll need your help. You can support us in any number of ways for example becoming a member, making a donation or becoming a campaigner.

Please support us today to help transform the lives of generations to come. To find out how you can help visit [www.rethink.org](http://www.rethink.org), phone 0845 456 0455 or email [info@rethink.org](mailto:info@rethink.org)

## **Information on mental health**

For more information about Rethink publications and other products on mental health, please visit [www.mentalhealthshop.org](http://www.mentalhealthshop.org) or call 0845 456 0455.

## **Make a donation**

We cannot achieve our goals without the vital funds donated by supporters. Donate today by calling 0845 456 0455 or donate online [www.rethink.org](http://www.rethink.org)

1. The Meaning of Independent Living in the Third Millennium. Talk delivered at University of Glasgow Centre for Disability Research, May 1999.
2. People get Ready: Music and the Civil Rights Movement of the 1950s and 1960s, Brian Ward, History Now, June 2006
3. Experiences and expectations of disabled people, Office for Disability Issues, 2008
4. How to Win Campaigns, Chris Rose, May 2005
5. Chris Rose, *ibid*

# rethink

Working together to help everyone  
affected by severe mental illness  
recover a better quality of life



For further information on Rethink  
Phone 0845 456 0455  
Email [info@rethink.org](mailto:info@rethink.org)  
[www.rethink.org/campaignwithus](http://www.rethink.org/campaignwithus)

Registered in England Number 1227970. Registered Charity Number 271028

89 Albert Embankment, London, SE1 7TP

Rethink is the operating name of National Schizophrenia Fellowship, a company limited by guarantee



Printed on 100% recycled paper

© Rethink 2008