# rethink



# breaking down the wall of discrimination faced by people with mental illness

# **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.

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# Introduction

In twenty-first century Britain, people affected by severe mental illness still face a wall of discrimination. People crash into this wall daily, doing simple things that others take for granted, like going on a holiday or applying for a job.<sup>1</sup>

#### "Every time I walk down the main street here I break into a sweat. You don't know what people are going to say to you."

Service User, Northern Ireland

It affects people's whole lives, limiting access to employment, volunteering and education. It affects how families see their relatives and how people see themselves.

#### "The stigma and discrimination I face daily is probably the only thing keeping me from getting back to where I want to be."

#### Service User, Northern Ireland

Rethink is working to improve individuals' attitudes and behaviour. Our pilots in Norwich and Northern Ireland produced measurable improvements in individuals' attitudes to mental illness. The antistigma campaign which Rethink is leading as part of the Time to Change partnership will make an even bigger difference.

But we cannot deal with the issue of mental health discrimination solely on an individual by individual basis. Both national and local government need to wake up to its responsibilities by promoting better public attitudes to mental illness and eradicating discrimination in public services and public policy. The law still treats people with severe mental illness as second class citizens – it says that mental illness is not compatible with being a Company Director, a member of a jury or a Member of Parliament. These arcane restrictions leave our public institutions bereft of representation from a sizeable proportion of the population.



Finally, as a community, people affected by severe mental illness increasingly demand that democratic representatives take their responsibilities to this two million strong constituency seriously. We need a civil rights movement in severe mental illness. The gains made by the physical disability movement have not yet come to fruition for people with severe mental illness, even though disability discrimination legislation covers all disability groups.

#### "When I was in hospital for mental illness, my friends did not come and see me. When I was in hospital to have a tumour removed, many people came to see me and brought me flowers."

#### Service User, Norwich

So what can we do about it? Our approach must be multi-faceted, tackling public attitudes, the policy and practice of government, public services and private enterprise and encouraging the empowerment of the community as a whole. In particular, we need:

- campaigns that make a real difference to public attitudes and behaviour
- national policy change by government to eliminate discrimination

 a mental health civil rights movement which empowers people to take action and demand these changes

Whilst the three interrelate, this report will look at the second issue: what policy change do we need from national government to break down the wall of discrimination faced by people affected by severe mental illness? Our companion publications *Breaking the silence* discusses how to create a civil rights movement in mental health. *Breaking Prejudice* considers the evidence base for antistigma campaigns.

Discrimination affects people with severe mental illness in so many ways, it is sometimes hard to know where to start. Rethink's *Breaking Down the Wall* campaign focuses on the following issues:

- restrictions on people with mental illness sitting on juries and on boards of companies
- the obstacles for people with severe mental illness trying to move into employment and voluntary roles

We hope in the future to be able to tackle wider issues, including the discrimination faced by people with mental illness in obtaining insurance and travel concessions.

#### **Your Shout**

Part of this report is based on survey data from Rethink's *Your Shout* survey, which was commissioned as part of the Rethink Politics project and disseminated in two different versions in England and Northern Ireland for a four month period (May-August 2007). We received over 1,000 responses.

#### Demographic profile of respondents:

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

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

**Ethnicity:** 85% of respondents were White British, but of the other ethnic groups the largest was the White Irish group. Only three 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 (35%) and Presbyterian Church in Northern Ireland (27%). Figure 1: Table showing the response rates to the paper and online versions of the *Your Shout* survey in England and Northern Ireland.

	Number
England paper questionnaire	804
England online questionnaire	111
Northern Ireland paper questionnaire	113
Northern Ireland online questionnaire	8
Total	1036

**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.



## **Rethink Politics**

Rethink Politics is a ground-breaking project funded by the Electoral Commission between 2007 to 2009. The project aims to identify the barriers people with mental illness face in participating in the democratic process.

In addition, the project includes a campaign to increase the awareness, confidence and participation levels of people with mental illness in the democratic process.

#### No place for me

Hundreds of thousands of people live with a severe mental illness in the UK and many of them have recovered a meaningful quality of life. Whilst severe mental illness is not 'curable', it is possible for people to achieve recovery, by getting the right help and support.

About 25% of people diagnosed with schizophrenia will make a full recovery; about 60% of people will have fluctuating symptoms; about 10-15% of people experience long term incapacity.<sup>2</sup> It is possible for people with severe mental illness to play an active role in the workplace, social groups, families, voluntary organisations and civil society. 58% of people with schizophrenia can work if supported through Individual Placement and Support.<sup>3</sup>

Rethink's 8,000 members include people from all walks of life who live with mental health conditions like schizophrenia, bipolar disorder, personality disorder and severe depression. Our membership includes scientists, published authors, secretaries and senior managers. There is no set 'type' of person that develops a mental health condition – mental illness can affect anyone.

Yet British law explicitly excludes people with mental illness from performing some of the most important roles in our society. For many minorities in society, we measure progress in terms of the proportion of people who take on important roles like Company Directorships or membership of the Houses of Parliament. Yet for people with severe mental illness, we are decades behind, as many of these roles remain legally off limits.

Many of our most feted institutions may as well have 'no people with mental illness allowed' signs above the door, exactly the opposite of what a socially inclusive society should accept.



# Jury service

Apart from people who are unable to meet the age and residence requirements, or who have criminal convictions, people receiving treatment for a "mental disorder" are now the only group who are ineligible for jury service in the UK.

Jury service is a key component of civil participation and citizenship. Yet UK law states that an individual cannot serve on a jury if s/he:

"suffers or has suffered from mental illness, psychopathic disorder, mental handicap or severe mental handicap and on account of that condition... regularly attends for treatment by a medical practitioner." <sup>4</sup>

This means that people with a severe mental illness are excluded if they are taking medication, undergoing psychological therapy or even seeing their GP regularly in relation to their condition, even though symptoms may be fully managed. It is

A letter came through the door in late November, and on the first page it explained that I had no choice but to attend for jury service within two weeks. Then I turned over the page, and reasons for not attending were required together with who was not eligible to attend jury service.

On the form it suggested that I would not be eligible if I was regularly seeing a psychiatrist, and then I felt deflated, and realised that the sender had no idea of my situation. The implications of stigma I felt were very real.

If I am able to teach university students Third World Development, and English as a Second Language students Information Technology then obviously my state of mind couldn't be too bad. I have been trained as a teacher and to be very aware of equal opportunities, and disabilities, and in some respects this is a kick in the teeth to all of that.

**Teacher and mother** 

perverse that people should be denied this right to participate in civic life when they have achieved selfmanagement of symptoms.

Anyone who is genuinely incapable of jury service should be excluded, but millions of people taking treatment for mental illness are capable of sitting on a jury and are being unnecessarily excluded from this important civic duty. This causes real distress to people who are trying their best to manage their condition.

Of the 193 countries in the world, approximately 80 of them allow their citizens to participate in the administration of justice through various forms of jury service. Of these, we have found just one place in the English-speaking world which operates a similar policy to the UK: Quebec.<sup>5</sup> Other Canadian states only exclude people who do not have the capacity to sit on a jury.

Most state laws in America also relate to capacity. Texan law allows individuals to be excused from jury service on the basis of physical or mental impairment. Floridian law includes no ineligibility criteria relating to people with mental illness. Californian law excuses people who have a 'mental disability' if serving would cause risk of mental hardship. The international picture shows that the UK is falling significantly short in its current approach.

This discrimination runs counter to many aspects of UK government policy. Public Service Agreement no. 15, which is one of the 30 targets for national and local government which have been set by the Treasury and will run from 2008/9 to 2010/1, gives a target of increasing participation in public life by disabled people. The definition of disability in the 1995 Disability Discrimination Act (DDA) includes mental illness. A 2005 amendment to the DDA widens the scope of this definition to include all mental health problems, whether or not they have been diagnosed.

I have always been someone who wanted to serve Queen and country; I trained at Sandhurst as an Officer Cadet after my A-levels. I was diagnosed with schizophrenia twenty-two years ago, but I have found ways to manage the condition and have continued to be an active and contributing member of society ever since.

I have spent 8 years serving as a fire-fighter, performing a public service and saving lives. I have even been awarded a Chief Fire Officer's commendation. More recently I was summoned to appear as a witness and gave evidence in a Crown Court, a service to society I was happy to carry out. So when I was invited to serve as a juror a year ago, I was pleased to do my civic duty. But I was rejected; told I could not sit on a jury because of my diagnosis.

There was no investigation into my mental capacity. If there had been it would be discovered that my illness is well-managed. I am a professional freelance trainer these days, and I'm quite sure I'd make a good juror. This rule excluding me from jury service is unfair and it makes me feel left out of mainstream society.

It doesn't make sense; how can I be trusted to save lives as a fire-fighter but not trusted to sit on a jury?

James Wooldridge

The *Pathways* pilots and the new Employment and Support Allowance regulations are based on the premise that current Incapacity Benefit or Income Support claimants with mental illnesses can and should be working full-time. It is inconsistent to suggest people should be working, yet cannot be trusted to be a juror.

750 people a month are disqualified from jury service on mental health grounds.<sup>6</sup> We asked respondents to the *Your Shout* survey if they had been excluded from jury service: 14% of the sample had. With 1 in 4 people experiencing some form of mental illness at some point in life, this equates to millions of people in the UK population.

Government seeks to increase the diversity of jurors, in terms of race, to try and ensure that juries treat people from minority ethnic communities more fairly. However, the Government is failing to do this for people with disabilities like mental illness. People with mental illness are unfairly treated by the criminal justice system.<sup>7</sup> For example, witnesses with mental illness often have their diagnoses used against them to allege that their testimony is unreliable. It seems logical that a juror with experience of mental illness is more likely to understand the experiences of a witness or defendant with a diagnosis than someone who has no knowledge of mental health issues. Addressing jury discrimination may help to reduce, in a small way, wider discrimination against people with severe mental illness in the criminal justice system.

What should the Government do? First, the Ministry of Justice needs to hold a consultation on this issue, as promised four years ago.<sup>8</sup>

The aim should be to exclude people on the basis of their capacity to be a juror, not on whether they have been 'labeled' mentally unwell at some stage in their lives. It is right that anyone who lacks capacity for jury service should be excluded, and anyone who thinks jury service would damage their health should be entitled to excuse themselves. The Mental Capacity Act 2005 established the first definition of capacity in British law. This could be used as a basis for a new exclusion, which would make a fair assessment of someone's ability to adequately discharge the duties of a juror.

If the law is changed and more people with mental illnesses end up serving as jurors, courts will need to be educated on the kind of adjustments people may require in order to participate.

# **Company boards**

Government policy is now focused on supporting people with mental illness to work. Yet, the law is explicitly barring people from the highest echelons of corporations.

#### The 1985 Companies Act states that:

"a person shall be ineligible for appointment to the Board and if already appointed shall immediately cease to be a Board Member if the relevant individual... is, or may be, suffering from mental disorder and... is admitted to hospital in pursuance of an application for admission for treatment under the Mental Health Act 1983 or, in Scotland, an application for admission under the Mental Health (Scotland) Act 1960"

Neither the 1989 or 2006 Companies Acts, which both revised the 1985 Act, changed this provision in any way. A similar provision exists regarding membership of the House of Commons.<sup>9</sup> Company Directors who have physical illnesses are not covered by any similar provision.

Of course it is right that while a person is so ill that they need to be treated without their consent, that person is unable to take decisions as a member of the Board for a short period of time. It is sensible that a person's appointment to a Board is temporarily suspended during a period of illness. However, this should be defined in terms of mental capacity rather than mental illness and provision should be made for people to return to the Board after they regain capacity. Currently, the Companies Act does not provide for any return to membership of a Board when the person has recovered. Their position should be kept open just as it would be if you had a physical illness.

Company Directors who have experience of mental illness could provide important leadership and ensure that mental health issues are dealt with better within the organisation. Boards are meant to set an example for organisations to follow, but the law does not help to ensure that members with mental illness are treated well by the most senior figures in businesses and other organisations. Whilst it would be wrong for someone to remain as part of the Board while lacking mental capacity as this could impact negatively on the organisation, it is also wrong for people to be suspended in the same way as criminals simply because of an illness.

Organisations have to comply with legislation on Company Directors. Therefore the Government should use the opportunity of the Equalities Bill to replace this provision with a criterion based on mental capacity.

"Despite the fact that I am a Director of an NHS Trust, have been a Trustee of numerous voluntary organisations and have been invited onto many government working parties and advisory groups, I would not be allowed to remain a Company Director. It is a myth that people with mental health problems are unable to contribute all of the time. Like many long-term physical illnesses, there may be periods when a person is unwell and unable to work, but do we sack people with heart disease or diabetes from their Director positions? No we do not – they may simply be absent for periods when they are not able to fulfil their duties.

Like people with these longer-term health conditions, most people with longer-term mental

health problems are not permanently 'ill' and, like those with physical health conditions, should have the right to use their skills during that majority of their time when they are able to do so. This example of discrimination enshrined in the Companies Act persists despite 13 years of anti-discrimination legislation. It is not only

unjust, but a dreadful waste of talent. It prevents the many people who occupy the higher echelons of our companies and communities from contributing their talents at the highest level. It must be changed now."

> Rachel Perkins, Vice Chair of Rethink Board of Trustees



# **Employment**

People with mental illness have the highest 'want to work' rate of any group of people with disabilities.<sup>10</sup> Yet, the actual employment rate for this group is one of the lowest: 13.3% compared to 59% for those with difficulty hearing.<sup>11</sup> Of *Your Shout* respondents, 66% were not currently in employment and 19% were currently employed.

We know more than ever how to support people with severe mental illness into work. US research suggests that 58% of people with schizophrenia can work if supported properly.<sup>12</sup> Rethink actively recruits people with personal experience of using mental health services and who may consider themselves to have a mental health problem. Rethink has found that staff who have a mental health disability or have used mental health services are no more likely to have a higher level of absence than other staff.<sup>13</sup>

Government now has a commitment to improve employment rates, both part and full-time, for people with severe mental illness under Public Service Agreement 16 (PSA 16 is one of the 30 targets for national and local government which have been set by the Treasury and will run from 2008/9 to 2010/1).

In theory, the aspirations of people with mental illness, the research evidence and government targets match perfectly. But in reality, employment rates are yet to change for people with severe mental illness. What needs to change for people's aspirations and government targets to become reality?

#### **Employer prejudice**

One of the main obstacles for people with all mental illnesses to getting work is the attitude of employers. 75% of employers say that it would be difficult or impossible to employ someone with schizophrenia.<sup>14</sup>

We asked respondents to the *Your Shout* survey if their employment experiences had been affected by mental illness. Half of *Your Shout* respondents felt that they had to hide their mental health problems; the second most commonly cited effect was not putting in an application for a job (41%) because of their mental health experiences.

	Number	%
Yes	198	19
No	686	66
Never worked	49	5
Other	79	8
Not stated	24	2
Total	1036	100

Figure 2: Table showing whether respondents were currently employed.

"I have an honours degree in Education but never got to teach in spite of many interviews. At this point I had only been in the mental health system for less than two years. The Job Centre made me re-train and I did a Business Admin course, but I couldn't even get a job in filing after 86 applications. I felt useless, rejected and the motivation and enthusiasm I had struggled so hard to retain, was fast disappearing. It had a huge impact on my mental health.

I lost all belief in myself and seemed to lurch from one mental health crisis to another. I felt as if I had diagnostic labels stamped on my head and when people approached me and saw them – they turned away."

Angela Warren now works in service user involvement in social work education.

#### What can be done about these issues?

Employers need education, support and legally enforceable bars on discrimination. Whilst the Disability Discrimination Act imposes duties on employers in relation to employees with mental illness as well as other disabilities, few employers really understand duties under the Act. Long-term culture change is essential, but there are short-term

#### Reasonable adjustments for severe mental illness

Rethink is working on a three year project to develop tools for local authority employers that will identify and help implement reasonable adjustments for people with severe mental illness. If you have a severe mental illness or are a carer and would like to contribute your experience or if you work in a local authority and would like to get involved, please contact Rethink's campaigns team.

Employers and employees need to understand mental health issues much better. Large employers could ensure that all employees or named leads have mental health awareness training through programmes like Mental Health First Aid or Rethink's Education Not Discrimination programme in the same way that some employees receive First Aid training.

Mental Health First Aid courses help members of the general public, including people in work, to learn how to respond to a mental health crisis situation. This intervention has been tested through the research methodology Randomised Controlled Trials. Rethink's Education Not Discrimination Training has so far been targeted at medical students and the police and is now being extended to trainee teachers.

Training interventions are particularly relevant for public bodies which have stronger duties to promote disability awareness under the Disability Equality Duty. The Scottish Executive aims to have 6% of the adult population trained in Mental Health First Aid by 2010. Public bodies should provide this kind of training as part of Disability Equality plans. National government, in its turn, needs to ensure that the Disability Equality Duty is not watered down under the new Equalities Bill. legislative measures and national policy change which could help with the second problem of people being deterred from applying for jobs.

UK employers are able to ask job applicants whether they experience a disability. Rethink has heard reports of some application forms asking people whether they have been sectioned under the Mental Health Act.

US Disability law does not allow employers to ask people if they have a disability until after a job offer has been made. The Americans with Disabilities Act states that employers:

#### "shall not conduct a medical examination or make inquiries of a job applicant as to whether such applicant is an individual with a disability or as to the nature or severity of such disability."

Pre-employment questionnaires are only allowed if they relate to "the ability of an applicant to perform job-related functions." This ensures that it is easier to recognise cases where employers have discriminated against potential applicants: 16,000 charges are filed under the Americans with Disabilities Act every year.<sup>15</sup>

Figure 3: Table showing the percentage of respondents whose employment experiences have been affected due to their experiences of mental illness.

	Percentage Mentioned
Not putting in an application for a job	41
Being dismissed or forced to resign	29
Denied a job	22
Threatened or attempted dismissal	9
Denied promotion to a higher position	10
Having to hide my mental health problems	50
None of these	23

A similar system would be particularly helpful for people with mental illness in the UK, whose disability or health condition may not be obvious to an employer at interview. In time, such a system could also benefit employers who currently turn away good candidates because of prejudice and discriminatory attitudes. 85% of employers who do employ people with mental health conditions are satisfied.<sup>16</sup>

Rethink believes that the new Equalities Bill, due to pass through Parliament in Spring 2009, should include a provision to restrict the use of pre-employment questionnaires and bring British equalities law in line with the American system.

One disadvantage of changing current legislation would be that organisations would not be able to run the current 'two tick' system, under which applicants with disabilities are guaranteed an interview if the basic criteria for the job is met. However, recent research suggests that in fact, these preferential employment programmes do not lead to better employment outcomes.

"One in six of the working population will have a mental health problem in any one year. Mental ill health does not preclude our ability to work and should never stop a person from getting a job they can do. Pre-employment questionnaires are discriminatory and should not be used in this way. We call upon public services, especially the NHS, to lead by example and end this practice."

Dr Bob Grove, Sainsbury Centre for Mental Health Employment Programme Director

Consideration should also be given to ensuring that people with valid causes for legal action over disability discrimination receive the necessary financial assistance to pursue a claim. Changes to legal aid may mean that fewer people are able to afford legal assistance to do so. The Government should consider setting up a special fund for these cases, as in the long-term, clarifying and strengthening case law in this area would benefit a large range of people.

#### **Time to Challenge**

Time to Challenge aims to challenge discrimination against people who experience mental health problems by taking cases through the courts. These cases will concern points of law that have a public importance and relevance to all service users. This will help to establish a wider understanding that discrimination on the grounds of mental health is no longer acceptable.

Time to Challenge, is led by MIND and is one of the project's included in the Time to Change programme.

#### **Employee support**

Support for people with severe mental illness to get into work is patchy across the UK. Some local authorities and Primary Care Trusts (PCTs) consider these services a priority, but not all. Rethink provides 30 employment support services under contract to PCTs and local authorities but few are financially secure in the long-term.

The *Pathways* pilots focusing on claimants of Incapacity Benefit should have ensured that people with mental health conditions received targeted support, given that more than 40% of claimants have a primary mental health diagnosis.<sup>17</sup> However, even Department for Work and Pensions (DWP) research concludes that there is 'no statistically significant evidence' that *Pathways* interventions benefit people with mental illness.<sup>18</sup>

Some people have been supported through Condition Management Programmes, which aim to help participants to understand and manage their health condition or disability. However, in Rethink's experience of delivering these programmes, too few people with severe mental illness are referred to these programmes from prime contractors to deliver a benefit to the majority.

#### **Rethink employment service**

The Kiosk was launched in April 2007 and is an innovative Rethink employment and training service for people with mental illness. Volunteers work in a refreshment takeaway service to the general public who use the Borough Gardens in Dorchester.

The Kiosk provides preparation for work in a community setting. This includes training, education and life skills leading to nationally accredited qualifications in hospitality and catering and helps those that wish to move on into paid employment in the community.

To meet their 80% employment target, the DWP needs to commission employment services that are really targeted to the needs of people with severe mental illness. Personal advisers working directly with claimants in the first round of *Pathways* pilots admitted that they lacked knowledge of mental illness and found these claimants the most challenging.<sup>19</sup>

There seems to be little reason to think that generic private providers will be more skilled and successful in supporting this group of people. For providers who are motivated by profit, there is a clear incentive to 'cherrypick' and prioritise support to people closer to the labour market and ignore those with more substantial needs. Currently, there is no agreed 'distance travelled' measure under which providers could be rewarded for helping people to take steps towards work. In the absence of an agreed measure, providers are rewarded on the basis of how many people move into sustained long-term employment.

JobCentre Plus could help to make the prime contractor model of *Pathways* (where the DWP has contracted an organisation or consortium to provide a *Pathways* service) more responsive under the current model by putting certain conditions on contractors. Prime contractors could have to show proof, for example, of training on mental illness for all employees, delivered by people with real experience of mental illness.

#### Training the professionals

Since 2000, Rethink has worked with the Institute of Psychiatry, King's College London to deliver antidiscrimination 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 to pilot delivery to trainee teachers at four teacher training colleges / universities across 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.

Pathways contracts also need to be monitored very carefully to ensure that people with mental illness, particularly some diagnoses categorised as 'severe', are not being written off by providers keen to prioritise people who need less support to enter into employment. Where contractors do seem to be sidelining certain groups, swift action needs to be taken to terminate the contract and bring in providers with the requisite experience.

In the long-term, JobCentre Plus and the DWP need to develop a 'distance travelled' measure so that there are financial incentives for providers to cater for people with a range of needs. As a first step, providers should be rewarded for helping people to achieve outcomes other than full-time employment, especially part-time work. This would be in line with PSA 16, which specifies part-time as well as full-time employment outcomes for people with severe mental illness.

Given the levels of employer discrimination discussed earlier in this report, it is essential that employment services also engage with employers in the long-term. They should reach out to employers, who might not consider employing people with mental health conditions, with information and advice. Also employment services need to support people with mental health conditions in the longterm to sustain employment.

### **Benefits and part-time work**

People with severe mental illness taking steps towards employment need to feel that the benefits system is supporting these steps, not acting against them. Yet currently, the complex interactions of different benefits means that people can end up on lower incomes when moving into work than when on benefits. The Government has identified that one of the most significant barriers in accessing employment is the 'difficulties moving from benefits to work'.<sup>20</sup>

But the benefits system provides numerous disincentives against making the transition from benefits to work. People on Incapacity Benefit are able to work for a limited number of hours per week under the 'permitted work' rules, without affecting benefits. This could be a useful way for people who have not worked for a long time and might find the prospect very daunting to get used to the workplace. These kind of rules could also allow people who are only able to work part-time to use skills.

However, the interactions between Incapacity Benefit and Housing and Council Tax Benefits mean that people are unable to use this system to its full potential. For one year only, people can earn up to £88.50 per week, which allows people to work at least one 'real' shift per week. Research suggests that this scheme does help people to get into employment.<sup>21</sup> However, under current Incapacity Benefit rules, if people earn over £20 per week for more than a year through employment with a private company, Housing Benefit and Council Tax Benefit are cut. This means that to protect incomes, people are unable to do more than 4 hours work per week. This is hardly a stepping stone for people into a fulltime job - under this system, it's impossible even to complete one full shift in most jobs.

The Government did agree to review these interactions as part of the new Employment and Support Allowance. Improvements have been made, but only for people on the income-based version of the benefit, in other words those people who have not paid enough National Insurance contributions. People on the contributions-based version, who have paid into National Insurance, or who became incapacitated at a young age, will continue to lose any earnings from work done. These people will also not automatically be passported for benefits like Housing Benefit, free school meals and free prescriptions. Some people will be up to £2,500 worse off per year than people on the income-based benefit. It is unfair that people who have paid into the system will be worse off than people who have not been able to.

The Government needs to devise a system which allows people to take meaningful steps to employment and, where full-time employment is unrealistic, allows people to undertake part-time work without losing income. This would be in line with the stated government ambitions under PSA 16.



The DWP does not regularly monitor the interactions of different benefits for people with disabilities. Tax benefit model tables are published quarterly for single parents (these are designed to show the hypothetical weekly financial circumstance of lone parents claiming benefits). As a first step to addressing the complexity of the benefits system, the DWP needs to publish these tables for people with disabilities. To make the tables even more comprehensive, consideration should be given to 'passported' benefits.

# Alternatives to paid work

Even if we manage to overhaul the benefits system and provide targeted employment support to people with severe mental illness, we need to accept that some people may not be able to work at some times – or ever. There need to be valued alternatives for people who simply cannot pursue paid work.

People who are not able to do paid work may still have valuable skills to contribute to local communities and public bodies. At the moment, too many people not in employment live in social isolation and are forced to scrape by on meagre incomes that cannot sustain a decent quality of life. This has negative impacts on local communities who lose out on people's skills, on individuals, who have a low quality of life, and on overall health, as social isolation is a predictor of poor mental health.<sup>22</sup>

What can we do to encourage people to participate? First, public and private bodies need to reach out more effectively to marginalised communities. Second, benefit disincentives to participation need to be removed.



Public services in particular have duties to promote disability equality in the way the organisations operate. How many have programmes to involve people with severe mental illness in the running of their services? As well as improving individuals' lives and health outcomes, such programmes would ensure that there is more social contact between people with severe mental illness and other people in the community. The social contact theory is well-evidenced in mental health as a way of improving people's attitudes and behaviour.<sup>23</sup>

In fact, when people offer to help, public services often respond with discriminatory attitudes.

"I have applied to become a volunteer at four different NHS hospitals and all four declined to take me on – first they accepted me, but as soon I as informed them I had a mental health difficulty – straight away they decided not to take me on. They claimed I posed a threat to the public – because of my mental health difficulties. Though I have never committed any crimes or acts of violence against anyone, they used my mental health difficulties against me."

University student with mental health condition

Public bodies should monitor how many volunteers have mental health conditions and seek to increase the diversity of their volunteers.

People who cannot work need a secure income to ensure that people can afford basics, especially in the worsening economic climate. People living on benefits long-term are often very close to the poverty-line, as long-term costs stack up.

Government repeatedly promised that the new Employment and Support Allowance (ESA) would be more generous for the main group than the current long-term rate of Incapacity Benefit (IB).<sup>24</sup> In fact, some people will be worse off. The base rate of ESA is identical to the long-term rate of IB, rather than higher. But the smaller range of rates and circumstances mean that the majority of individuals will be worse off by £1.85 per week and most couples would be worse off by £12.85 per week. Because of the end of age allowances, people under 35 could be £17.75 worse off per week.

People need to receive an income that means that they can participate in society. These lower income levels could leave people in poverty, which will not help the Government to reach its current aspirations on child poverty. The Government needs to ensure that ESA levels increase.

Benefits rules also need to ensure that for people unable to work, participation in voluntary work does not lead immediately to reviews of entitlements that effectively discourage people from participating in communities. Rethink has dealt with many cases where people have engaged in voluntary work and then had their benefit entitlement reviewed.

Government has taken a helpful step by changing regulations for Employment and Support Allowance so that people with disabilities who take part in consultations by public bodies will be able to be paid for participation without losing benefits. However, as with the changes on permitted work, these changes only apply to people who are on contributions-based benefit. Again, we can see no reason why people who have paid contributions should be treated worse than people who have not.

## Support in work

Since 1994, the Access to Work programme has existed to fund support for people with disabilities that enable people to work. This programme, however, does not currently help people with mental illness to any substantial degree. Over the last five years, around 25,000 people per year have been helped by this scheme, but only 1% of these people had a mental illness of any form.

The DWP has discussed making this support available to people in voluntary roles as well as paid roles. However, given the current poor levels of access for people with mental illness, it is more pressing to ensure that the programme reaches out to people with a variety of disabilities.



## **Education**

The poor level of mental health awareness of many staff within educational institutions, means that students with mental illness are not receiving the vital support they need. Further, the lack of understanding and knowledge of mental health amongst students, places those with mental illness at risk of discrimination, bullying and isolation from their peers. Discrimination within educational establishments needs to be challenged.

There is currently no legal requirement for staff within educational institutions to receive training in supporting students with mental illness. This needs to change. The Government needs to ensure that mental health awareness within schools, colleges and universities is improved by:

 All staff being given training in mental health so that they can better support students and colleagues who are experiencing mental illness.





let's end mental health discrimination

# Rethinking student mental well-being

Rethink is working with the University of Central Lancashire in Preston to raise awareness of mental well-being among students and staff, with the aim of encouraging students to seek early help if they are experiencing mental distress.

Rethinking Student Mental Well-being is part of the national Time to Change programme.

The project aims to:

- challenge stigma and to encourage students to seek help
- improve mental well-being through physical activity
- develop a pathway of support for students with mental health issues
- develop a good practice guide for other universities

- Mental health awareness to be included in PSHE or citizenship lessons, to improve student understanding of mental illness and help to end discrimination.
- All educational establishments being required to promote disability equality for students with mental illness and to take action to stop bullying.

"I started getting bullied when I started secondary school. At first it wasn't that bad but when I got to Year 9 it started to get worse and it got so bad I had to change classes twice. By year 10 I was running home in tears and trying to tell the teachers who would never listen, they said it was my fault and that I brought it on myself.

I was even excluded once for something I never did which was proven, but the teacher still didn't listen even though someone came forward to say I didn't do it. They never understood my situation.

I never had many other friends at school and when the main people that bullied me stopped they used to be nice to me and I used to fall for it, but as soon as I did they just bullied me again. Sometimes some situations got so bad I felt the police should have been involved but again the teachers never listened.

When I left school I felt like I was being released from prison or escaping hell. They ruined my life. When I left I couldn't go out anywhere or go to college because I always thought they were there and always thought everybody was like them. I could hear their voices still in my head.

This went on for about a year and when I was 17 I had a breakdown. I was admitted to hospital where I stayed for a week shortly after coming out I tried to kill myself twice. All though what they did to me."

**Rethink Involvement Worker** 

# **Recommendations**

#### Jury service

- The Government needs to carry out the public consultation on jury service and mental illness promised in 2004.
- The current law barring people from jury service who receive treatment for mental illness needs to be changed. The exclusion basis should be based on mental capacity.

#### **Company Directors**

- The ability to perform the role of Company Director should be defined in terms of mental capacity rather than mental illness.
- A provision needs to be created, where by a Company Director can be temporarily suspended during a period of mental ill health, but to be able to return to the Board after they regain capacity.

#### **Employer attitude**

- The use of pre-employment questionnaires needs to be restricted to bring British equalities law in line with the American system.
- The Government should consider setting up a special fund for employment and mental health discrimination cases, as in the long-term, clarifying and strengthening case law in this area would benefit a large range of people.
- Large employers should ensure that all employees or named leads have mental health awareness training.

#### **Benifits system**

 The Government needs to devise a system which allows people to take meaningful steps to employment and, where full-time employment is unrealistic, allows people to undertake part-time work without losing income.

#### **Employee support**

- The Department for Work and Pensions (DWP) need to commission employment services that are targeted to the needs of people with severe mental illness.
- *Pathways* contracts need to be monitored to ensure that people with mental illness, particularly some diagnoses categorised as 'severe', are being supported. Where contractors do seem to be side-lining certain groups their contracts need to be terminated.
- JobCentre Plus and the DWP need to develop a 'distance travelled' measure so that there are financial incentives for *Pathways* providers to cater for people with a range of needs. As a first step, providers should be rewarded for helping people to achieve outcomes other than full-time employment, especially part-time work.

#### Alternatives to work

- There needs to be valued alternatives for people who simply cannot pursue paid work.
- Public and private bodies need to reach out more effectively to marginalised communities.
- Public bodies should monitor how many volunteers have mental health conditions and seek to increase the diversity of volunteers.
- Benefit disincentives to participation need to be removed. Benefits rules need to ensure that for people unable to work, participation in voluntary work does not lead immediately to reviews of entitlements.

#### **Education**

- Staff in educational establishments should be given mental health awareness training.
- All educational establishments should be required to promote disbailty equailty for students with mental illness and to take action to stop bullying.
- Mental health awareness training should be included in PSHE or citizenship lessons at school.

# Conclusion

Discrimination impacts on people affected by severe mental illness everyday. No one policy change can eliminate this. No one government department so far has taken responsibility for challenging it on a wide enough scale.

However, government does have the power and a responsibility to make sure that its own policies and the legislative record do not add to the discrimination that people have to face. These changes are often in the interest of government and would enhance the current reform programme.

Future policy change by government will increasingly need to be 'mental health proofed'. Rethink has supported calls for a mental health champion at Cabinet level to ensure that the needs of the millions of people with mental illness are put at the heart of government policy.

Rather than promoting policies and legislation that actually add to the discrimination that people face, governments of all colours need to ensure that policy and legislation actually help to challenge discriminatory behaviour rather than embody it.

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Sign up to join Rethink's Breaking Down the Wall campaign at www.rethink.org/campaignwithus or phone the campaigns team on 0845 456 0455.

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









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