



**For better
mental health**

Improving the Life Chances of Disabled People

Response from Mind

April 2005

Mind works for a better life for everyone with experience of mental distress, by:

- Advancing the views, needs and ambitions of people with experience of mental distress.
- Promoting inclusion through challenging discrimination.
- Influencing policy through campaigning and education.
- Inspiring the development of quality services that reflect expressed need and diversity.
- Achieving equal civil and legal rights through campaigning and education.

Autonomy, equality, knowledge, participation and respect are the values underpinning Mind's work.

1. Introduction

- 1.1 Mind is pleased with the Government's political commitment to improving the lives of disabled people, including people with mental health problems. We very much welcome the shift in Government stance on which model is most appropriate when thinking about disability, from the medical to the social model. As is stated at various points throughout 'Life Chances' and has been argued for a number of years by disability groups, it is very often the attitudes of non-disabled people and the design of policy and systems, rather than a person's impairment which limits their lives. We are also pleased that Government has recognised the particular difficulties experienced by people with mental health problems.
- 1.2 However, we are disappointed that there does not appear to be any allocation of new money to this ambitious programme. The Government sets out its laudable vision of facilitating full opportunities and choices for disabled people to improve their quality of life and for disabled people to be respected and included as equal members of society. As is acknowledged in 'Life Chances', this will require a step-change in the way the disadvantage faced by disabled people is dealt

with. If this vision is to be realised, financial as well as political investment has to be committed.

- 1.3 We are concerned about delivering this far-sighted and ambitious scheme within a central Government system over compartmentalised in styles of working, ethos and financial structures. Much thought must be given to a propelling mechanism, both within the civil service and at a political level, that will overcome these barriers and keep up the momentum of change.

2. Independent Living

- 2.1 We applaud the principle driving Government's plans for a system where people with support needs are allocated a personal budget to spend on the support providers that they choose. If disabled people are to be truly independent, then it is right that they should decide what kind of support they receive and who provides it.
- 2.2 Yet there remains cause for concern. The extension of direct payments in the past two years has revealed the lack of integration of mental health services with mainstream social care, causing serious difficulties for mental health service users. This means that there is and continues to be a very low base of service users already "in the system" and few professionals supporting and advancing assessments and care planning. In addition there is a lack of infrastructure in the provision of social care for people with mental health problems. In other disciplines, direct payments co-ordinators had a greater capacity to move service users straight to direct payments management of their existing packages of care by transferring budgets. Because budgets for social care in mental health services were hard to identify and the professional input so small, there has been correspondingly little administrative capacity to set schemes up, and an apparent unwillingness to dedicate resources.
- 2.3 In addition mental health service users who need help in their own homes are particularly vulnerable to various forms of abuse. The Protection of Vulnerable Adults (POVA) register is not available in direct payments administration and service users report that access to the Criminal Records Bureau is often denied. This paucity of protective mechanisms must be corrected if the proposed system of individualised budgets is to work for mental health service users.
- 2.4 The administrative burdens of running a care package can be complex and onerous. Although support should be available, poor administration in mental health services does not necessarily deliver this. This disadvantage is compounded by a lack of trust in mental health service users; and the psychological difficulties that many service users experience as part of their disability (for instance, a lack of confidence or self-esteem).

- 2.5 Part of the plans to enable disabled people to choose and buy their support services must include modelling of different methods of administering the financial elements of service delivery. Systems need to be developed that make the contracting of support services as uncomplicated as possible.

3. Employment

- 3.1 Mind absolutely supports the Government's intention that any disabled person who wants a job, and needs support to get a job, should be able to do so wherever feasible. We believe support to employers - and enforcement action where necessary - are essential, and agree with a personalised, tailored service to individuals. Particular mental illness diagnoses do not preclude working and no-one should be written off in employment terms on mental health grounds. However this is very different from saying that anyone with a mental health problem can think about working at any given time, or that they will in fact obtain or sustain work.
- 3.2 As individuals point out, wanting to work is not the same as being capable of it and in a survey of people with mental health problems living on benefits almost a third said (often very emphatically) that they were too unwell to work. So whilst it is right that people who express an aspiration to move into employment are supported in doing so, the starting point of any such support must be a realistic assessment of an individual's capability. It would be entirely counter productive, and damaging to mental health, to move a person into work before they are ready, even if that person perceives themselves to be.
- 3.3 We urge Government to recognise that employment is not always an option for all people with mental health problems and to ensure that appropriate financial and non-financial support for disabled people not in work is embedded in any revised service system for disabled people.

Pathways to Work pilots

- 3.4 While Mind broadly supports Pathways to Work (PtW), there are some worrying indications from at least one of the pilots and we should want there to be careful evaluation and learning from it. These range from the underlying tone of the invitations to interview stating the sanctions for non-attendance, through advisers' felt lack of knowledge and awareness of mental health issues, to jobs not working out perhaps because of lack of in-work support.
- 3.5 In addition, Department for Work and Pensions (DWP) research on the PtW pilots shows that there is a perception amongst Incapacity Benefit Personal Advisers (IBPA) that the key purpose of the PtW programme is to move claimants into work. IBPAs also expect a target regime that will reinforce this perception at the expense of supporting claimants to build confidence, explore training opportunities or even remain on

benefit where this is appropriate.¹ This research also shows a lack of knowledge amongst IBPAs about the 'Choices' packages including the condition management programme. Other concerning findings include a lack of private rooms in which to interview claimants and a style of communication that gives the impression that claimants must comply with all they are asked to do by their IBPA or lose all benefit.

- 3.6 We ask that due emphasis is placed on full and through training of all front line staff and that this training is regularly reviewed and that service users play a central role in any review of training packages.

Occupational health

- 3.7 When people with mental health issues raise the subject of occupational health services with Mind it is more often as an obstacle to employment than a solution. Practice may well be changing but they still seem often to be associated with screening people out of jobs. The recommendation for occupational health (7.2a) should also address Disability Discrimination Act (DDA) implementation by occupational health staff.

Vocational rehabilitation

- 3.8 We agree with more and/or better vocational rehabilitation but would want to include in that advice/advocacy on employment rights, and career review or counselling. People who have gone through a major emotional or mental health crisis may be re-evaluating their lives, with the potential for significant, positive changes. Some people may need a significant break (without losing hope and access to vocational support) - current thinking seems to be if you get in early enough, everything is all right.
- 3.9 We believe that service user input into rehabilitation policy and practice should minimise the possibility of the imposition of unrealistic and/or inappropriate expectations on people with mental health problems.

GPs

- 3.10 The more informed and aware GPs are of good rehabilitative practice, positive approaches to mental health at work, people's ambitions to work and the resources available, the better. However we would be concerned at over-policing GPs' role and practice in certifying sickness. A local Mind association job retention initiative suggests that GPs would be only too happy to encourage people with mental health difficulties to access employment support services where these are made available. It may be still be appropriate though to sign people off work for a period. The decision to certify should be well informed, but not influenced by targets or quantitative performance indicators.
- 3.11 Whilst working to enhance the role GPs play in facilitating people who want to return to work to achieve that goal, it is worth noting that GPs

¹ Dickens et al (September 2004) *Incapacity Benefit Reforms – early findings from qualitative research*
DWP

don't have any control over people's workplaces. Where a claimant's employer does not operate best human resources practice, an earlier return to work sanctioned by a GP may have detrimental consequences for the mental health of that claimant. This is not to ignore the possibility that a person's home environment might equally be detrimental to their mental health. Rather it is to highlight that GPs may not always be aware of all relevant factors when deciding whether to sign someone off work, and so may unwittingly facilitate a return to a work environment that further worsens their patient's mental health.

- 3.12 In light of the above, we call on Government to ensure that an individual's whole life circumstances be taken into account by decision-makers, including GPs, when they assess whether or not a person with mental health problems should return to or take up work.

Benefit Assessment & the Capability Report

- 3.13 We welcome Government plans to review eligibility assessment for disability-related benefit, but we urge caution. DWP plans to overhaul the IB system provide a prime opportunity to dispense with the long-standing shortcomings of this benefit, but these should not be replaced by new deficiencies. It is essential that benefit claimants, mental health services users and other stakeholders are provided with real opportunities to contribute to the design of the new system.
- 3.14 A key role of the IB Personal Adviser (IBPA) is to assess support needs and employability as part of the capability report. Only with these additional assessments can there be any chance of claimants being supported into work that meets with their skills, knowledge and aspirations and at a pace appropriate to the claimant. For this to work, IBPAs will need to carry out thorough assessments of claimants' life and work-related skills in a sensitive and supportive manner.
- 3.15 The recent record of Medical Services in accurately assessing the health of people with mental health problems is poor.² Whilst the Medical Services contract has recently been tightened and re-tendered, the primary difficulty of the service being provided, in the main, by locum doctors with no expertise in mental health has not been addressed. Without a dedicated well-trained workforce it is difficult to see how the standard of medical assessment can be maintained at an appropriate level. To date IBPAs don't always refer to other sources of information about the applicant's health, for example Community Mental Health Nurses, counsellors or other support workers.
- 3.16 Currently there is little clarity about how 'manageable conditions' or 'severe functional limitation' will be defined. We have some concerns about how these have been defined under the pilots. At the moment guidance in the IB Handbook for Approved Doctors suggest that severe mental health problems are suggested by:

² Social Security Committee (2000) *Third Report: Medical Services*

- a need for ongoing psychiatric care which may include sheltered residential facilities with regular nursing care
- day care of at least one day a week with qualified nursing care available, long term medication with anti-psychotic drugs including depot neuroleptics or mood modifying drugs or,
- where a person's condition severely restricts their social functioning or means they are likely to pose a threat or danger to others.

We are not convinced that mental health problems that do not meet any of the above criteria are always by default 'manageable conditions'.

- 3.17 The conditional nature of higher rates of benefit is of major concern. It is easy to imagine scenarios where claimants agree to action plans, which they may not be able to fulfil, for fear of losing benefit. Other claimants may well feel confident that they are able to meet commitments agreed in their action plan, but subsequently experience a mental health crisis and become unable to carry out their action plan. It is unclear how much influence claimants will have over the contents of their action plans. Nor is it clear how benefit sanctions will be implemented if a claimant does not agree or fulfil an action plan.
- 3.18 It is not clear to what extent people with mental health problems may fall foul of the penalties for 'lack of co-operation'. Personal Advisers, unless their training is very good, may well interpret behaviour that is related to mental health difficulties as uncooperative behaviour.
- 3.19 We recommend that IBPAs training includes contact with service users, separate from those they are working with, with the aim of increasing IBPAs understanding of the reality of living with a mental health problem and how this impacts on their lives.
- 3.20 As yet the DWP have given no indication of what any appeals system might be like. Linked to this is the issue of moving between the two types of benefit. Given the fluctuating nature of mental health problems, it is likely that people with mental health issues will need to move from RSA to DSA and vice versa. The administrative procedures of these two benefits and their interaction with each other has to be designed so that movement from one to the other is simple and does not present a barrier to appropriate transfer.

In-work Support Through Access to Work

- 3.21 We welcome the proposals around the reformation of the Access to Work scheme. Key to making this scheme work for disabled people is correcting the anomaly where, because of the budget-limited nature of Access to Work funding, people meeting the eligibility criteria do not have a right to receive support for an identified need. Access to Work should be a statutory right for all disabled people.

- 3.22 Current funding of the scheme is inadequate. In its Interim Report, the Work and Pensions Select Committee recommended, 'that the Access to Work budget should be increased by a significant proportion', whilst in another report the same committee saw Access to Work as providing 'crucial and cost effective support to disabled people and their employers'.³ Part of any increased funding allocated should be used to increase awareness of the scheme amongst employers – in 2002 the British Chamber of Commerce found that 74% of employers did not know about Access to Work.⁴ This is particularly pertinent given that under the DDA, an employer can legitimately not carry out an adjustment if the financial cost to the employer of doing so would be unreasonable.
- 3.23 Currently the route from application for support to provision of that support can be subject to lengthy delays and often support is not in place for the initial period of employment. For an individual with mental health problems this lack of support can mean losing their job if they experience a mental health crisis and have no support in place.
- 3.24 Volunteering provides an effective route into employment. Therefore we believe that access to volunteering opportunities should be facilitated by Access to Work or an equivalent scheme where necessary.

Job Broker Activity

- 3.25 Mind views job brokerage as a basically sound model in that it provides for a personalised service that is proactive in securing jobs for people. However the Life Chances document cites worrying evidence of serious shortcomings in the core functions of this service – securing the right job for the person, having good links with employers and creating awareness of the service among disabled people and employers. Even the language of the report – 'Disabled people are often not matched to the right job' – implies a bureaucratic process that is done to disabled people, rather than a service to disabled people as customers/clients with aspirations and ambitions.
- 3.26 We agree with, and have advocated, a case management approach and therefore support its development. However we have concerns about whether the PtW pilots are delivering a satisfactory case management service and whether plans are in place to ensure that they do. We agree with the recommendations at 7.12 and recommend urgent action on making vacancy filling client-led. Furthermore these improvements should be in place before there is any question of tightening the gateway to benefit.
- 3.27 While Jobcentre Plus is the obvious place for a case manager role, people often prefer to see an independent organisation or adviser. We therefore recommend that Jobcentre Plus make the best use of

³ Disability Employment Coalition (2004) *Access to Work for disabled people* RNIB

⁴ British Chamber of Commerce (2002) *Budget Submission*

voluntary sector providers, by for example, commissioning mentoring, support, job retention or advocacy services and staff training and development.

- 3.28 We welcome attention to addressing financial issues in the risks of transition to work, but would like to see acknowledgement of people's other concerns, such as those around capability in the job and not letting the employer down, and housing insecurity.

4 Towards Improved Delivery

4.1 Government must have regard to the failures in mental health services as a result of institutional change. Substantial change in the organisation and delivery of health services and the integration of health and social care since 1997 have had a great impact on service delivery on the ground. The differing goals of health and social care have been recognised by the former Social Services Inspectorate (SSI) as being capable of detracting from key social care priorities. In its outgoing report, the SSI commented that, although most councils were fully involved in joint Local Delivery Plans for investment in mental health, "39 per cent reported that resulting Plans did not reflect key social care priorities, with investment being focussed on a small number of new services prescribed by the NSF, and on meeting cost pressures in the NHS".⁵

4.2 The integration process itself is long and complex, sometimes diverting the energies of service providers and de-railing services. As new services are shaped, those seeking help will be confronted with a great variety of providers, ranging across local authorities, NHS trusts, CMHTs and joint services of many kinds. This has led to confusion and unfulfilled expectations.

4.3 The impact of chronic underfunding on social care for people with mental health problems has reverberated throughout service provision. At the heart of many of the practices and choices of service providers and service users is the critical issue of resources. Referral of a potential service user to the community team could relieve the local authority of the costs of social care. Clinical outreach and support provided by the NHS may be treated as substitutes for services that the local council might otherwise be forced to provide. Also, high thresholds for entry into the social care system, such as restricting assessment to those under CPA, ensures that fewer people will be admitted to the system.

5 Implementation

5.1 The creation of a core team taking forward implementation in the form of the Office for Disability Issues (ODI) is to be cautiously welcomed. We note with disappointment though, that no new resources will be made available to the ODI from the outset. We are concerned that the

⁵ Social Services Inspectorate, *Treated as People. An overview of mental health services from a social care perspective, 2002-04*. Department of Health 2004, paragraph 5.3.

ODI might be characterised by the limitations affecting the National Institute for Mental Health in England (NIMHE), which has been charged with taking forward the implementation of the recommendations of the Social Exclusion Unit's report into mental health and social exclusion.

- 5.2 The central co-ordinating NIMHE team is, to a large part, staffed by funded and unfunded secondees. Despite the best efforts of this team and the associated regional NIMHE social inclusion leads, the social inclusion programme is already slipping. Initial funding of the core team amounted to a mere £175,000, so ability to increase the capacity of the central team has been limited. Lessons should be learnt from the experience of NIMHE. If the ODI is to achieve its role of overall co-ordinating body it must be sufficiently resourced in terms both of staff and funding. To scrimp on this fundamental element of the programme is to jeopardise the whole project. We believe that the ODI can only benefit from having disabled people, including people with a history of mental health problems, on its staff.
- 5.3 We support the creation of a National Forum of Organisations of Disabled People, but call once again for proper resourcing. We also urge Government to ensure that organisations representing mental health service users are a core part of the Forum.
- 5.4 Nevertheless we additionally believe that people with direct experience of the issues this office is concerned with will offer a uniquely informed perspective that will be invaluable in shaping the development of the programme. We therefore urge Government to be proactive in encouraging the recruitment of disabled people, including people with mental health problems, onto the ODI staff.
- 5.5 Indicators of the improved nature of the lives of disabled people will not always be quantitative. Government should accept the validity of 'softer' measures of improvement by, for example, regularly seeking the views of disabled people on how they feel their lives may or may not have improved over time.

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