



Bipolar Disorder – Gaining and Retaining Employment

A Wales-wide Research Project involving those with the Disorder and those who employ them.

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1. Foreword

Work can help us to define who we are, release our creativity, offer social contact, provide financial choice, and bolster a sense of independence and of self-worth.

The lack of work, and the financial options it brings, can lead to isolation, and the opposites of all of the things outlined above.

Work is important to all of us. It is no less the case for those who carry the increased burden (in finding and retaining appropriate employment) of being 'bipolar'.

This piece of research shows how the onset of Bipolar Disorder (what used to be known as Manic Depression) defines and heightens these things.

The stories set out here – for that is what they are: human stories – are insightful about the extra burdens this 'condition' imposes on those who have Bipolar Disorder.

We made a conscious choice, at the start to create the conditions where those with Bipolar Disorder spoke for themselves about the importance of work for them, and about their experience of trying to find and maintain work.

We also made a deliberate choice to 'case study' (ie go in to much more depth with) a number of 'successful' stories – that is, people who are in work and have been successful in work, and/or those who were maintaining well-being whilst in work. Our thinking around this was based on good evidence (backed up by sound theory) that highlighting what does work - success - leads to good learning and change.

The project was co-funded by Healthy Minds at Work, the European Community (through its EQUAL project), and by MDF The Bipolar Organisation Cymru.

I was pleased to be asked to lead this research project, and humbled by its findings.

Recognition and thanks go to Dr. William Fear for his central input as research advisor to the project and his co-authoring of this report; to Colin Williams Director of MDF The Bipolar Organisation Cymru, who was instrumental in raising the idea of, and negotiating funding for, the research; and to the organisation's group development coordinator Sue Wigmore. The four of us made up the team who did the interviews at the heart of this research.

MDF The Bipolar Organisation had the foresight to 'open its membership list' in order for the research to be carried out.

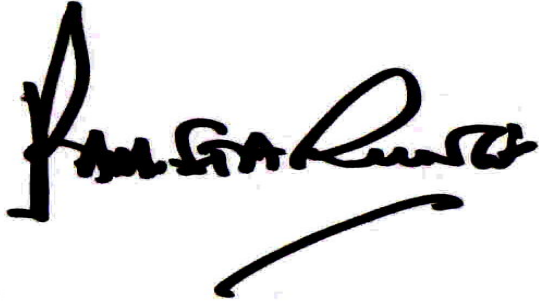
More than ten percent of its 525 members participated. Everyone who took part has been diagnosed with Bipolar Disorder.

What emerges in these 'stories', is not theory at all but the direct, 'lived', experience of those with – Bipolar Disorder.

What also emerges are insights which, while showing what does work, what does help, those with Bipolar Disorder maintain a sense of well-being within this context of work, also

casts a light on how much more needs to be done to help, encourage, and support those with Bipolar Disorder to achieve, and (to whatever extent), maintain their economic independence.

We should be grateful to those who agreed to take part for their honesty and their courage.

A handwritten signature in black ink, appearing to read 'Paul Starling', with a long, sweeping underline stroke extending to the right.

Paul Starling, Research Project Manager.

[Note: We are, of course, addressing several different audiences, with this final report. Some of the report is written in 'academic' language. We hope that this is not off-putting.

The heart of this research is the experiences of those with Bipolar Disorder. We provide a '*background*' to the work which, once read, can lead directly in to the heart of the research which is the '*results*' section. From that emerges '*recommendations*' for action.]

2. Executive Summary

1. This Report provides insights and evaluation of the experiences, perceptions, and expectations of those diagnosed with Bipolar Disorder in relation to gaining and retaining work. Our focus was on the way Bipolar Disorder affects their ability to work, and to maintain a sense of well being while working. The aim was to better understand, from an objective point of view, what those with Bipolar Disorder have found effective for job retention. This is in contrast to 'what they want', or 'what they think they need'. Taking a more objective view allowing us to begin building a stronger, and more informative, evidence base. Our focus, also, was to gain the same understanding from the employers point of view.

2. We used qualitative methods well recognised and widely used in occupational research, including the use of the Critical Incident Technique, as the basis for interviewing around ten percent of the membership of MDF The Bipolar Organisation Cymru (525 members) who have all been diagnosed with Bipolar Disorder exploring what they found 'helpful' and 'unhelpful' in work situations, and those things they would have hoped for ('wish list'). From these interviews we selected in-depth Case Studies involving people who are in work and have been successful in work, and/or those who were maintaining well-being whilst in work. The rationale behind this approach was that there is good evidence (based on sound theory) that highlighting what does work leads to good learning and change). A critical review was completed which led to a summary at the end of the report, and recommendations 'in terms of 'actions', and 'conditions necessary' for those with Bipolar Disorder to gain, retain, maintain work and well-being.

The following are among the conclusions drawn in the Summary:

3. The CIT technique proved to be a powerful way of accessing peoples' experiences while at the same time achieving 'necessary objectivity'.
4. What shocked us was the small number of helpful incidents compared to the large number of unhelpful incidents and the even larger number of 'wish list' incidents. This was disappointing because we had hoped that the world of work was providing a greater level of perceived support than it appears to be here.
5. What we found was a consistent and emergent theme around support ... the clear way in which interviewees articulated the impact support had made to them demonstrates this as a key area'.
6. The biggest problem faced by people with a bipolar condition was disclosure. Experiences varied from disclosure having a profound change for the better to it resulting in further discrimination to the point of dismissal. Yet without disclosure there is no mechanism for people to either access or develop support.
7. Support is crucial. This was a consistent theme across the interviews, the case studies, and the employer interviews. Those with Bipolar Disorder, in a work situation,

do not want to be treated differently, or to have special conditions, but to be treated equally, fairly, with consideration and support that empowers them to function’.

8. The Case Studies provided powerful examples of how well people can manage when the support is available, and, in contrast, how bad things get when the support is either stripped away or not available. They also provided uncomfortable insights into just how wide and deep discrimination and stigma is in the workplace.
9. Those with Bipolar Disorder, in a work situation, do not want to be treated differently, or to have special conditions, but to be treated equally, fairly, with consideration and support that empowers them to function’. Special treatment or exceptional benefits could be disarming and disempowering.
10. The level of non- (or anti) support in the workplace can have a substantial impact on peoples’ lives ... the question is, ‘how do we make changes in the work place to overcome this?’
11. What people with bipolar conditions are asking for in terms of support to gain and retain remunerated employment is no different from what any reasonable person would ask and require. The findings were disappointing, because this is – when provided - good practice in any case, and does not require extensive and costly changes to be made by employers; and disappointing, too, because if the level of discrimination and stigmatisation levelled at people with a bipolar condition was levelled at, say, someone with ethnic minority status, or with a physical disability, there are mechanisms to engage with the employer to overcome this and to manage the consequences.
12. While the consequences of ‘anti-support’ for ‘others’ ranges from poor working conditions, frustration, and perhaps the need to change jobs and/or live with some frustration, the consequences for people with a bipolar condition can be devastating not only for them but also for those around them.

3. Recommendations

These are defined in terms of *actions* and in terms of the *conditions necessary* for those with Bipolar Disorder to gain, retain, maintain work and well-being:

- Being 'accepted' in a work (and social) sense for 'what they are' and as 'a person of worth' regardless of Bipolar Disorder.
- Most want neither to be treated differently, nor to have some form of special treatment.
- The value of 'support' both in the workplace (line management and/or colleagues) and beyond (family, partners, friends, community, GP, mental health professionals) is central – perhaps most important of all - to maintaining work, good working relationships, and well-being.
- Some form of support seems to be crucial to people retaining employment. Support and understanding in the work place seems to be most important of all.
- Greater 'understanding' of Bipolar Disorder by line managers (through background reading and education) is an important factor in the maintenance of work and well-being.
- More open-ness and willingness amongst employers to agree adjustments, and flexibility, in working patterns.
- The stigmatisation around mental health issues in the work place – and beyond - remains high.
- Open, supportive, line management can tackle much of the discrimination which can flow from such stigmatisation.
- Open, supportive, line management can tackle, early and at source, the *perceptions* of stigma and *interpretations* of the actions of others which can be a symptom of Bipolar Disorder and which can severely affect their ability to remain in work and in a state of well being.
- Open, supportive, approachable, line management is better able to deal with the clear examples which emerged of intimidation, harassment, perceptions and claims around 'performance'.
- Open, supportive, approachable, line management will go a long way to dealing with the ambivalence among many with Bipolar Disorder over whether 'to disclose' or 'not to disclose' their 'condition' to an employer.

- Supportive and understanding line management, linked to reasonable adjustments in work patterns, can ensure that people are better able to manage in the work place.
- The education of, and understanding by, line managers and colleagues are central to well-being, the choice to disclose and being open, and continued employment.
- There is a clear and strong need for greater education, awareness, knowledge, and understanding of Bipolar Disorder among the public.
- Their needs to be much clearer thinking, understanding, and action, among managers about support, lack of support, reasonable adjustments to work patterns, discrimination, stigma, and harassment.
- The experience of a number of participants of 'Personnel' or 'Human Resources' being directly involved in 'sacking' people can be undermining of confidence in employers.
- Clear definition of roles, responsibilities, 'realistic and reasonable targets', routines, the monitoring of workload, time management, monthly reviews and insightful assessments of someone's ability to do the work they are being asked to perform, the need for respite/time away from work, better understanding underpinned by respect and support, as well as a creative attitude towards flexible working by employers can have a real impact on the retention of work and well-being.
- Adherence, by line management, to disability, equal opportunities, health and safety and other requirements would ameliorate many of the conditions which can undermine those with Bipolar Disorder in the workplace.
- The clear shortfall in equality of opportunity and fair treatment needs to be addressed if those with Bipolar Disorder are to do meaningful and rewarding jobs where they are able to 'be themselves' and not receive 'special treatment' (ie: accepted as perhaps being different in some way but are not discriminated against because of this).
- There is a clear need for closer management and monitoring of professionalism of, adherence to, and understanding of the links between mental health, legislation, discrimination, and disability.
- A 'broker', type-friend in the workplace trusted by someone with Bipolar Disorder, who they can relate to and who can act as a 'go-between', could prove beneficial to employer, line managers, and (BP) employee, alike.
- An independent mentor, advocate, or counsellor would prove beneficial to employer, line managers, and (BP) employee, alike.

- Employment advocacy (from practical help with CV and Application writing, job identification and availability etc to negotiating issues with employers) is likely to be beneficial to employers and those with Bipolar Disorder seeking work.
- Overall – Support - in the workplace from friends, colleagues and management (which would include mentoring/advocacy) and professional support that ranges from good diagnosis and medical advice through to work-related and community support. Employment - good practice: flexible working, and fair, professional, properly trained and educated managers. Tackling discrimination – by educating employers and public; providing job seeking and job retention support; helping with and advising on disclosure; tackling stigma.

4. Background

The aim of this research project was to gather insights directly from those who know best what it is to live with Bipolar Disorder – those who have been diagnosed with what used to be known as manic depression.

Our focus was on the way Bipolar Disorder affects their ability to work, and to maintain a sense of well being while working.

From the outset, (and recognising the time and resource limitation), we chose to complete a specific piece of high quality work rather than address a more disparate set of questions. The arguments for engaging with those with Bipolar Disorder, in the work itself, are well rehearsed in the literature and elsewhere (e.g. empowerment and the use of methods such as Appreciative Inquiry, User-led research, and so on).

The objectives of the project were:

- To establish those ‘services’ and forms of support those with Bipolar Disorder consider to be helpful and effective to help them retain jobs/work. These things based upon their: a) personal experience; b) perceptions; c) expectations.
- To determine what employers consider feasible in terms of job retention for those with Bipolar Disorder based on their: a) personal experience; b) perceptions; c) expectations.
- To compare and contrast the findings from 1) and 2) above within and between those with Bipolar Disorder, and employers.

The rationale for these objectives is clarified below.

Context:

One of the conclusions of this report is (and a recognised starting point, was) that there is a marked sparsity of research.

There is a growing body of literature on job support interventions for people with mental illness (and/or ‘common mental health problems’, or whatever particular label one chooses). However, the literature seems notably biased towards ‘job support’ programmes for individuals without addressing the needs of the employer. With regard to those with Bipolar Disorder, specifically, there is perhaps less research available on job retention, particularly in the UK. There also appears to be a gap in the literature on why some people are able to retain long-term remunerated employment while others are not. We don’t really know why this is. This focussed piece of work begins to provide elements of answers.

Bipolar Disorder has received limited attention and exploration compared to other mental illnesses. Elgie and Morselli (2007) found that those with the disorder tend to experience high levels of social disruption including hostile family attitudes. In addition they found high levels of stigma, delay in correct diagnosis, and high levels of unemployment and low

levels of retention of employment. This is mirrored by the work of Lerner, Adler, and Chang et. al. (2004) in relation to depression. They found that people with depression experienced greater job upheaval than controls with rheumatoid arthritis and had more job turnover, presenteeism, and absenteeism (an important consideration for those with Bipolar Disorder in relation to the depression element of the condition).

As regards remunerated job development and support, Leff, Cook, and Gold, (2005) found that job development helped with job acquisition, but that job support had no demonstrable causal effect either on job retention or hours worked. Any contribution of job support was confounded by vocational counselling. The study looked at severe mental illness, not any one specific mental illness, and did not give definitions of job development and support. It appears to rely on an assumed shared understanding of the terms in psychiatric literature.

Morselli, Elgie, and Cesana (2004) repeated a pan-european study of Bipolar Disorder and concluded that in recent years there has been a consistent improvement in the perceived quality of life but there is still much to be done in relation to social functioning and integration and that those with Bipolar Disorder still bear an onerous burden, whichever European country they live in.

A further consideration that does not appear to have been addressed, in the UK, is that of comorbidity. Comorbidity with substance abuse (including alcohol) is common among depressives and those with Bipolar Disorder and in one study accounted for the high suicide rates in those with Bipolar Disorder (Verduin, Carter, and Brady, et. al. 2005). Comorbidity could reasonably be expected to impact heavily on job retention when it is linked to substance abuse.

What we lack is an understanding of what people affected by mental illness, and those with Bipolar Disorder in particular, have found effective in the workplace over the longer term (three, five and seven years). (See for excellent example, Flatt 2005. This can also be contrasted with the lack of accessible and coherent literature of this sort in the UK.)

This research aimed to accomplish three things in relation to the objectives. First, to better understand, from an objective point of view, what those with Bipolar Disorder have found effective for job retention. This is in contrast to 'what they want', or 'what they think they need'. Taking a more objective view allowing us to begin building a stronger, and more informative, evidence base. Second, to gain the same understanding from the employers point of view. Third, to share these ideas and observations across the vertical divide.

The sponsoring organisations – MDF (The Manic Depression Fellowship)/Bipolar Organisation Cymru and Healthy Minds at Work [see Appendix I] - reflected this aim of bringing those with Bipolar Disorder directly into the context of the world of work.

Amongst the stated aims of MDF the Bipolar Organisation Cymru is the intention to 'enable all people with bipolar disorder in Wales to take control of their lives', 'expanding and developing the information services about bipolar disorder', 'influencing the treatments and services to promote recovery', 'decreasing discrimination against people', and 'promoting the social inclusion and rights of people affected by' bipolar disorder.

The project, its outcomes, conclusions and recommendations are consistent with those aims.

The Research Approach:

Three hundred and sixty invitations to take part were sent out to members of MDF The Bipolar Organisation Cymru. [Appendix II]. Almost a fifth (70 members) volunteered to participate in the first phase of the research. In the event, (taking in to account the time-frame, those who chose to change their minds about participation, and the fact that the interviews were conducted during the summer 'break') 53 were eventually interviewed. This involved a telephone interview exploring (and recording – in confidence) questions around whether each participant member was in work, for how long, the type and sector of work, whether they are settled in that work or would prefer (or have preferred) to do other work. Core questions were then explored around whether the employer knew if the member had bipolar disorder, if so how that emerged, if not why was the decision taken not to declare. [Appendix III defined the overall approach. Appendix IV the specific Interview Report/Recording Form used]. A small number of participants were contacted and fed back via e- or postal mail [Appendix V]

The findings of what participants found 'helpful', 'unhelpful' in work situations (regarding bipolar disorder, attitudes, disclosure etc) were all categorised and databased, using what is known in (and accepted as a robust model by) the academic community as the Critical Incident Technique. Participants were also asked to define what they would have hoped for (what we defined as a - 'wish list') in a work situation. These findings were also databased.

The second phase of the research aimed to conduct further (and longer) interviews with eight-nine of the participants. These aimed to go in to greater detail and depth and provide a 'case study' base involving around 10% of those participating. [Case Studies below, and Appendix VII – Initial decision-making notes re participant case studies]. In the event seven participants were either prepared/or available to be interviewed as 'case studies'. These all involved (what at the time of decision-making appeared to be 'successful' cases - that is, people who are in work and have been successful in work, and/or those who were maintaining well-being whilst in work (thus fitting well with the emerging 'fitness model'). The rationale behind this approach was that there is good evidence (backed up by sound theory) that highlighting what DOES work - success - leads to good learning and change. (Based on what is known as the success case method/appreciative inquiry/ amongst other names and recognising that the problems/barriers people with Bipolar Disorder face would emerge, anyway, from the whole of the interviews (what is unhelpful etc).

'What services would I like to see? Free high-level career counselling for bipolar professionals. Government funding for small business loans for bipolars. Research on the best working environments for bipolar professionals, tips on coping with job-related problems, a hot-line for immediate work-related problems, government tax breaks for companies that are willing to provide flex-time schedules for bipolars or job-sharing arrangements, free seminars on how to find a job when you're depressed, grants for bipolar writers and artists, and the list goes on. Personally, I don't find it uplifting to read stats on how many bipolars are unemployed and how many problems we have in work situations.'
Susan Bernard,
Professional Writer, 2007.

The purpose of the Case Studies, then, was to understand how people successfully manage being in work. The method was to use open ended interviews asking people to

talk about what they feel has really made a difference. What do they think has enabled/empowered them in the work place. Is it one thing, or is it many things? We explored the working environment people are in and have been in. Are/were they in stressful jobs, or have/had they opted for jobs that have less stress. Was this a conscious strategy, or did it end up this way. What are the strategies people use to manage work. Do they have one or many strategies. How important are other people, and who are the important people. Are there additional mechanisms that make a difference? For example, do policies in the work place make a difference? How important is disclosure, and so on.

The point was to look for 'lessons', and 'models' of success.

The third phase of the research involved attempting to conduct interviews with employers who are employing, or have employed members with Bipolar Disorder (stressing, as throughout the process, that everything was in complete confidence, and done with the full knowledge and agreement of all involved).

The fourth phase was a critical review of the categories and the examples (involving feedback from some of the participants).

The final phase involved the authors drawing together the experiences, evidence, responses, answers, reactions from the whole process.

This report is the result.

[[Note: The outputs and outcomes from the research (defined at the start) can be seen at Appendix (VI).]]

NOTE ON TERMINOLOGY: The term mental illness has been used to denote a continued lack of well being and disability in the workplace as a consequence of some form of recognisable psychological or psychiatric condition. This does not include 'stress'.

5. Methodology

'---most employers run at the very mention of severe mental illness---then if you try to find a position in another field---you are questioned repeatedly why you can not work in your trained field---...---my own therapist tries to get me to just quit work and live off of disability---' BamaGal (2007)

Rationale

Our aim was to capture the experience, perceptions and expectations of those with Bipolar Disorder regarding job retention support; and the matched experiences, perceptions and expectations from an employer perspective. In order to do this we decided to use qualitative methods that are well recognised and are widely used in occupational research, and used the Critical Incident Technique (CIT; Flanagan 1957). We anticipated additional added value in that this would provide us with a bank of 'incidents', or categories of incidents which could then be utilised to for information, advice, and further training as well as highlighting perceived need.

Method

The project made use of a set of qualitative methods. We used interviews to collect work/employment related incidents from people affected by bipolar disorder. We then selected a subset of respondents for more in depth case studies. We selected those respondents who had successful experiences in relation to work. That is, they had been able to stay in employment and held either strong or well satisfied positions. We felt this was important to learn lessons about success and that these cases were best placed to inform us on what does work for this population. We also interviewed a small number of employees to obtain their views on what worked and what didn't work in relation to providing support for people with bipolar disorder in the workplace.

Instruments

For the interviews we used a version of the Critical Incident Technique (Flanagan). We revised a number of published templates and decided that the version used by Butterfield and Borgen (2005) had both the appropriate level of sensitivity (to the respondents' needs) and would adequately capture the data we needed.

An initial template was devised then discussed in depth with staff at MDF and adjusted according to that feedback. Important considerations regarding establishing rapport and taking account of respondents sensitivities were highlighted and incorporated.

A final CIT template was then produced, and this template was followed for the interviews. (Appendix VI).

For the case studies we selected seven respondents from the interviewees. They were all people who were currently in employment and had long term employment histories. We were also took account of the demands we were asking in revisiting these respondents to conduct case studies.

Further in-depth interviews were conducted with these respondents for these case studies focussing on how things could be improved for people affected by Bipolar Disorder. We took a lead from the 'wish list' items that emerged from the data set.

With employer interviews we used the same interview template but adjusted the wording to suit employers. (Appendix IX).

The CIT technique involves asking individuals about their experience and for specific details relating to that experience. The responses are categorised and the categories and examples are tested with a sub-sample of the respondents. Thus, people participating in the research play an active role in determining understanding and meaning. The CIT has been used with vulnerable populations (Butterfield and Borgen, 2005). We used a slightly modified set of questions as follows:

Tell me about your experience of being in work and staying in work;
What support did/do you receive that helped/helps you stay work and who provides this support;
What sort of things are not helpful to you when you are in work and trying to stay in work;
Is there any sort of support you don't get but which you think would be helpful?
What were your experiences which led to you leaving the work that you were doing?
(This last – for a sample of those who had not retained work). [See Appendix III].

The interviews were conducted by the authors, Paul Starling and William Fear, and by two staff members of MDF the Bipolar Organisation Cymru.

We sampled the membership of the MDF Bipolar Organisation (described above) to obtain a sample of those with Bipolar Disorder who are in work in order to provide case studies. It is important that these case studies are of remunerated employment as that will be the 'normal' challenge faced by most who have the Bipolar Disorder. In these case studies we specifically looked for those support structures that have facilitated successful employment. (While also extrapolating insights from those who have not retained such employment). The case studies covered, in depth, the person's background, and the structures and mechanisms they have used for support.

More rigorous sampling methods were not realistic for a study of this size, nor with this population. We were working with relatively small numbers of people, with limited resources, that preclude random probability sampling procedures. This is not an unusual scenario, and is well recognised. Opportunity sampling is a legitimate sampling method which knowingly constrains the inferences made from the results rather than the methodology itself.

For employers, we sought access to those we know have those with Bipolar Disorder in their employ. We recognised, from the outset, the sensitivities around this. The limited take up by employers reflects some of the findings, experiences, personal testimonies, and conclusions of this report.

Process

Members responded indicating their willingness to take part in the research. Participants were contacted by phone and either interviewed at the time of contact or a more suitable

time arranged. When respondents were interviewed the template for the CIT interview was broadly adhered to although respondents were not necessarily 'kept on track'. That is, we recognised we were working with a vulnerable population and that at times they may be more concerned about saying what they wanted to say rather than sticking to the interview guidelines. We do not consider this to have impacted adversely on the research. If anything, it helped gain and maintain rapport. We also had to be sensitive to the fact that this may be a difficult topic for some participants. For example, if they have not worked for long time they may be sensitive to this, and similarly if they are experiencing difficulties in work at the time of interview they may want to talk to about this to some extent.

Respondents were contacted up to three times to arrange interviews. After three 'contacts', including leaving a contact number for the interviewer, we were unable to conduct the interview we ceased further contact.

6. Results.

Three hundred and sixty invitations to take part were sent out to Bipolar members of MDF. Eighty two responses were received, seventy said that they would be willing to participate – in the first phase of the research. The sample was, therefore, a self-selecting opportunity sample. In the event, fifty-four people were interviewed.

(i) Overview of Response Rates and Socio-Demographic Breakdown.

The respondees live in all parts of Wales, from the cities of the south, the former industrialised valleys, the south, western and northern coastal belts, and west, mid and north Wales, making this the biggest research programme carried out in and across Wales among those diagnosed with Bipolar Disorder.

The number interviewed was 53.

Their ages ranged from 22 to 68.

The average age of the interviewees was 45. They included 20 males, and 33 females.

Of those interviewed: 7% were in their twenties; 16% in their thirties; the largest group (by far) 36% were in their forties; those in their fifties made up 23%; while the others: 17% were in their sixties.

Fifty-three percent of those interviewed were in work. Those out of work made up 39%. Others were either retired, or while still nominally employed 'on permanent health insurance' were not working because of the severity of their condition.

Of those not working around 17% were actively looking for work.

'In work' included full-time, self-employed, part-time paid and part-time voluntary.

The 'work' ranged from nursing, admin (assistant), teaching (assistant), chef/artist, joint caretaker, checkout operator, high profile media sector work, pub and restaurant work, work with an environmental pressure group, to self-employment, and running their own company.

There was a marked propensity for working in therapeutic type roles and settings. A number of those interviewed had used the insights from their own experience to become 'mental health advocates', another had become an occupational therapist, and another had created her own self-employment as an aromatherapist.

Employment profiles, therefore, varied tremendously from people running their own businesses to others working short hours with flexible options.

(ii) Critical Incidents

Explanatory Introduction:

The 'critical incidents' were sorted into three 'sets', incidents that were *helpful*; things that were *unhelpful*; and a *wish list*.

Each set contained a series of categories of incidents. These categories can be thought of 'things that were/are'. So, we have things that were/are helpful, things that were/are unhelpful, and things that people would like to see addressed (because they are either 'problems' or it would be helpful if they were in place. Indeed, the absence of the things that people would like to see addressed - is a problem in its own right).

Each category contains a number of incidents that go to make up the category.

An incident is an event, or an observation of an event or occurrence that relates to the category.

[Examples: A helpful category is, 'Acceptance of the illness and the person'. While within this category an incident that *exemplifies* the category is, 'My line manager accepted me and my condition'.

An unhelpful category is, 'Discrimination or stigmatisation (or the sense of being targeted and singled out)'. While within this category an incident that *exemplifies* the category is, '(One of the bosses she works for) "is domineering and because I have mental illness if I don't agree with her she says it's because of the mental illness"'.]

A wish list category is, 'Mentor'. Within this category an incident that *exemplifies* the category is, '(One of the bosses she works for) "Perhaps a mentor, someone who can be aware that there could be a problem, because often I couldn't see the signs my self, and they might be able to step in earlier and say, perhaps, take a day off"'].

We don't have the space here to go through every example of an incident in every category, and anyway, that isn't necessary.

What we will do is list the categories and explain what we think they mean. We have also provided a strong incident to highlight each category. We deliberately chose strong incidents rather than repeated incidents or mundane incidents.

It is important to recognise that the number of incidents in a category does not necessarily bear any relation to either the importance of that category or the validity of category.

Having said that, we did find that the incidents grouped together quite naturally and strong categories emerged.

We have listed the number of incidents per category.

We also need to bear in mind that the number of people citing an incident is not the issue. The incidents are what count - and the categories they form, and what they mean, is our concern.

Things that were helpful

We identified four categories of things that were helpful. These were:

- (1) Acceptance of illness and the person;
- (2) Supportiveness;
- (3) Understanding;
- (4) Adjustments in working patterns.

(1) Acceptance of illness and the person (4)

This category highlighted that when the person is accepted as a person regardless of their illness this makes a difference. It is strongly related to other categories and to the wish list categories. It revolves around social and work acceptance and the sense of being accepted as being a person of worth.

‘Later I had another bad manic breakdown, by then the management had more or less accepted my illness and didn't prejudice me. It helps with your self-esteem, which is a big thing. It helps you work better.’

(2) Supportiveness (30)

Supportiveness is a difficult category to define and explain not least because it is so broad. We were better able to get at this under the wish list where it was broken down into different categories. What emerges clearly is the value of support both in and outside of the workplace.

People gave examples of people who were ‘supportive’ and ‘sympathetic’ and who ‘had respect’. Mostly this support came from line management and from colleagues in the work place. In a smaller number of incidents it was support from friends generally, or a family member/s or spouse, and in an even smaller number of incidents mental health professionals were referred to (including GPs).

Some form of support seems to be crucial to people retaining employment, and support and understanding in the work place seems to be most important of all.

‘With my first manic breakdown my general manager was extremely sympathetic and supportive. When I went back to work I was relieved of some of my duties, I kept my job for a long time. I had time off (about six weeks).’

‘They are very supportive - the whole organisation. "If it gets too much I can lay it off on someone - I can go and get support, talk to someone, get understanding”’.

Two colleagues - including his line manager – were "especially supportive". "When I was on a high (and wanted to spend a lot of money) his line manager "persuaded me not to". When in a 'low' "very little was expected of me". They were “very, very, supportive”.

"Supportive husband and very supportive GP”,

In addition to this it was noted that it is crucial to maintain good working relationships in the workplace, and good support will help with this. Also, we need to be aware that most people neither want to be treated differently nor to have some form of special treatment. They want the support, which, they are entitled to. This links to the experience of problems with disclosure and poor treatment, or differential treatment, when people do disclose.

(3) Understanding (12)

When there is a degree of 'understanding' people seem to find this helpful. Understanding links to support but goes further. It includes line managers actively trying to understand the nature of the problem, including reading up about it. There are examples of disciplinary proceedings and financial settlements being waved because of 'understanding'.

Understanding does seem to be linked to disclosure and people seem to be confident and able to disclose when 'understanding' is present.

Her supervisor "did some research in to manic depression".

"There were potential disciplinary proceedings which were mitigated by their understanding of my condition. As well as the welfare officer, my immediate colleagues, and my line manager were understanding in so far as anyone can understand mental illness and be supportive. There was never a negative issue with my absences which far outweighed my attendances, and that put pressure on my colleagues".

"There was no bearing on customers of the business and the breakdown was obvious to clients - they were understanding".

(4) Adjustments in working patterns (8)

Interestingly, in this category, the adjustments people talked about were mostly adjustments they had made themselves. They talked about how they had adjusted their lifestyles to allow them to manage their work and their careers. There was little said about how employers had made adjustments.

"As a volunteer there is no pressure on me as to how many hours I work and when. Have not been unwell yet whilst at this school, so I don't know how they would react".

He felt that settling for early retirement helped him achieve a good recovery. The employer did not push him into this, but he realised the episodes would have become a re-occurring pattern

One striking thing about this category is that while the above were helpful incidents they were mostly things that the person had done/actions that the person had taken themselves. There was little to indicate that employers had been willing to make adjustments in working patterns.

Summary

Overall, the number of helpful incidents and categories was small and disappointing. We knew, at the outset, that the general consensus is that more needs to be done, and not enough is being done. We also knew that stigma, discrimination and prejudice were perceived to be high, and that reasonable adjustments and understanding were low (if present at all). Yet we wanted to challenge this and to find success stories and positive events to relay. We have achieved this, to some extent, with our case studies but, as the reader will see in the following sections, there is a good deal more which requires to be done.

Things that were unhelpful

We identified eight categories of things that were unhelpful. These were:

- (1) Poor treatment by line management;
- (2) Discrimination or stigmatisation (or sense of being targeted and singled out);
- (3) Stress and pressure;
- (4) Not being able to disclose;
- (5) Lack of understanding/empathy;
- (6) Lack of employment;
- (7) Lack of willingness to accommodate requirements/lack of support.

Some of these categories are mirrored throughout the three sets of categories, and some of them overlap with and between sets of categories. This is normal for this sort of research as an incident or event can be both helpful and unhelpful, and categories can readily overlap. This is because the incidents reflect real life rather than an artificial situation, and real life is complex and muddled.

What struck us was the number and intensity of incidents that were unhelpful compared to those that were helpful, and we have already noted our disappointment in relation to this. No doubt much of what we report here will be familiar and it is well recognised and reported in the literature. The added value we hope to provide here is that real people have been given the opportunity to tell us their experiences, their version of events, and to articulate what is important to them. There is a strong sense of 'voice' in the incidents and, underlying it all, a real sense that people are not relating their stories because they are, somehow, 'terrible' or 'awful' - but because they want something to be done, action to be taken, positive change to come about.

(1) Poor treatment by line management (3)

This highlighted just how bad things can become when line management decides that they do not want to accommodate someone with a disability.

'It was an extremely competitive company to work for. I felt consistently at risk of losing my job. It really exacerbated my illness. I was finally made redundant. All of a sudden I had a new boss, and all of a sudden I was out of a job. This new boss, and HR manager, came to my house and said "we are appointing a new market research manager, that it would

increase the stress on me, so I would be better off out of it. I was absolutely stunned. It took me two years to get myself together financially and emotionally. It was shabby - the way it ended. I was bloody exhausted but I think, maybe, I should have taken action. They made no suggestion or offer of any early pension. I was absolutely appalled at the way they treated me.'

There are further incidents that could arguably fit into this category but we felt that this small set of incidents were difficult to categorise elsewhere.

(2) Discrimination or stigmatisation (or sense of being targeted and singled out) (24)

This is a difficult category as it relates to how people perceive the situation and interpret the actions of others. People, clearly, may feel that they are being targeted or stigmatised when they are not. However, we need to recognise that discrimination, prejudice, and targeting are realities for people with mental health issues (for want of a better way of putting it), and that people with Bipolar Disorder can face greater difficulty than others in the workplace because of the difficulty of maintaining relationships.

We tried, here to gain a sense of how discrimination operated. It may be that it was not really any different to poor treatment by line managers. However, we felt the way in which these incidents were related highlighted how discrimination operated.

People reported being picked on in relation to performance, ('they would be extra tough on my mistakes'); having little or no support or incentive to stay in work; being openly intimidated, harassed, bullied, and sacked. Throughout it all there is an overwhelming sense of discrimination and stigmatisation, with performance commonly raised as a point of conflict. In other words, people are targeted for their performance and told their performance is not up to standard. Rather than being supported to improve, and manage, their performance, they are either edged-out or, blatantly, sacked.

'There was blatant discrimination against people with mental illness.'

Although she had told them she suffered from depression when she started the job, they were not supportive. After bouts of depression when she took some time off, she was called in for a meeting to discuss her sickness record. She found this 'very intimidating'. She felt too unwell to attend the meeting and was sacked. From the time of her first sick note to when HR rang her to arrange the meeting there was no contact to see how she was. Her line manager was not involved at all. She felt the meeting was an ultimatum, but nobody was allocated to give her any advice or help.

'I felt isolated, a bit different, in the canteen they would eat together, I was excluded, I would be on my own'.

One participant ended up in psychiatric ward. The organisation's Personnel Officer rang her husband to say they wanted to visit her. "He believed they were doing it to be supportive" "The next day the Personnel Officer came to the ward and said I had 24 hours to apply for my own job. I just ran up the wall, they had to get the patient's advocate and nursing staff they didn't know what to do with me. Can you imagine - it was my livelihood. That was what split my husband and I up in the end. The personnel officer came under

false pretences, I was beside myself. She handed me an application package when I was in a psychiatric ward, I didn't have my CV, how could I”.

Another worked in a 'business promoting' field. "Behaviour [when he was high] "was not businesslike". I was asked by my boss to explain what was happening. They sent me to see a doctor, they ended my employment based on what the doctor told them. I was never told what the doctor had told them. I appealed but they stuck to their guns”.

This, naturally, raises issues around disclosure, which also emerges in the wish list. There was a marked difference – and ambivalence - in view about whether ‘to disclose’ or ‘not to disclose. Many are reluctant to take that step.

‘If you tell employers, (and others), you are always open to prejudice. As long as you can do your job people don't need to know’.

‘The attitudes changed once I disclosed it. I felt that they viewed me as a bit of a liability. My line manager wasn't very comfortable when she did what she did which was asking me if I wanted to take a financial package...six months later my line manager came to me and said that they wanted to offer me a financial settlement. She raised an issue about my performance at that stage, which had never happened before’.

She feels her supervisor was scared of 'setting her off' and had a lack of feedback from her supervisor. At six months faults were raised in relation to her performance. She feels she lost her job through the fear of her employer who refused to make reasonable adjustments.

In relation to this, we should also note that ‘personnel’ or ‘HR’ were noted a number of times as being instrumental in sacking people. This, too, emerges in the wish list.

(3) Stress and pressure (16)

Most people we talked to, if not all, willingly and readily recognised that work is always stressful at times. They also recognised that they were often susceptible to this. However, we need to consider very carefully, as did the interviewees, that this is not reason for people not to take up stressful employment if it is what they enjoy and they are well suited to the post. There is a complex consideration here between the individual's susceptibility to stress and the employers understanding and appropriate responsibility towards their employees.

People reported a wide variety of situations that led to stress, none of them unfamiliar, unusual, or different to the those reported by any other person. In other words, we saw no indication that any one particular event was any more or less stressful to the people we interviewed.

There was some indication that people may have felt more susceptible to stress because of lack of confidence in themselves and their ability to cope.

‘The unsettled, spasmodic, working shift patterns unsettled me, I then had low self-confidence, low self-esteem’.

Also, lack of clear roles, responsibilities, and routines seemed to have an impact (which is actually normal. Most people experience work place stress in the absence or disruption of these). What was clear was that people recognised stress as a trigger for either manic or depressive episodes, or both.

'We moved offices to much worse offices with not much natural light. There was a lot of change and uncertainty about the work which I found worrying. There were more meetings than normal, it wasn't as pleasant, it affected my health with more episodes'.

Gets very stressed when under pressure. 'If not sleeping or eating well that makes you poorly'.

When the pressure is on he doesn't respond well to stress. His medication has reduced his energy and this leads to him being overloaded and he doesn't have a manager who helps manage his work load. Yet he feels he needs close management and realistic/reasonable targets.

(4) Not being able to disclose (15)

Following on from (2) above, people raised the difficulty of disclosure. There is no doubt that when people do disclose and this is met with support, understanding, and reasonable adjustment then people are far better able to manage in the work place. However, there is little to indicate that disclosure leads to this important triad of components (support, understanding, adjustment).

If anything, it seems that those who disclose and have a positive experience are in the minority.

Lack of disclosure created problems with people's own management of their mental health as they had to 'mask it', utilise external support, use their own time to manage their condition, and felt uneasy about not being able to be open.

'I was really a bit of a lie. Nobody knew that I had this condition and I didn't dare tell them'.

People recognise substantial problems with disclosure. The biggest is being treated differently, being under scrutiny, and having performance and ability questioned. This extends to telling people in the health professions.

And, of course, there is the relatively common experience of having employment terminated in some way: post-disclosure.

"I didn't want to be sectioned so I acted normally. Whenever I saw psychiatrists I would act absolutely normal. So nothing was diagnosed. It was the worst of all possible outcomes. My wife was left to deal with my mania and I had no medication. I kept having episodes, I was given the sack'.

"I was very wary of telling people up front. Maybe I should have declared it but I thought it was in my best interests not to. There has always been a huge problem declaring my MD to employers. I have always suffered in silence which is very difficult - you are always

wondering about does this person know me and that I have BP, it's a huge problem, really”.

Disclosing may lead to special treatment and participant doesn't know what would happen if he disclosed. He suspects it would lead to limitations being imposed. He did speak to a lawyer about disclosure but found this unhelpful. He had a manic episode in work, while involved as a contract worker, and employment was terminated. This sticks in his mind.

(5) Lack of understanding/empathy (21)

This category was of interest because the category of ‘education and understanding’ emerged so strongly in the Wish List (below). People find the lack of empathy and understanding very difficult. Problems with managing emotions and related behaviours are poorly understood in the workplace. Such lack of understanding links strongly to: lack of support, and to: discrimination and stigmatisation.

‘Unable to disclose’ should also be linked to the lack of understanding/empathy. And, of course, both play on the other. Were people able to feel they could disclose this would (might well) address (some of the) issues around understanding and empathy. However, people clearly feel, much of the time, that that risk is too great a one to take.

The lack of empathy was not really related to consequences, as some of the other categories were. Rather, it seemed attended by a sense of frustration and, at times, resignation.

‘Most people don't understand how we are feeling’.

‘Some people don't take your view seriously because you're bipolar’.

‘Employers are very, very, wary about employing anyone with bipolar, because they are ignorant’.

‘(Management are) always in a rush, you feel as if they are not really listening’.

‘If I was off, the work had doubled by the time I got back in. There was no empathy. No one to turn to. You wouldn't believe it, the company were not respecting of my mental illness’.

(6) Lack of employment (4)

Put simply, and baldly, people found being out of work a problem, and felt that they faced discrimination when seeking work.

- Because he was sectioned he feels the DHSS are very cautious about sending him back to work.
- She has had three failed attempts to get back into work because of bad experiences. The longer she is out of work the harder it is to get back in. She needs to build up

slowly and needs support. She needs: another pair of eyes; a sounding board; to speak to someone else first.

(7) Lack of willingness to accommodate requirements/lack of support (18)

People recognised their own need for support in the workplace. This ranged from simple ergonomic considerations like adjusting noise levels, or being able to move to somewhere quieter, through to a staggered return-to-work, and lack of 'support'.

In some ways we might see this category as subsuming all the above categories. We could say that the single thing that was most unhelpful for people with Bipolar Disorder was, and is, a lack of support - in all its forms.

Lack of support was sometimes specific to situations such as high work loads which were not adjusted, excessive travelling, pressurised targets, and lack of flexibility to manage the condition, all of which can be related to stress-inducing scenarios.

'I needed a greater level of support to stay in the job especially with the noise levels. That was something they could have done something about. I might have been still there if they had'.

'When I did ask for what was a reasonable adjustment, to make it easier to concentrate, they weren't prepared to do that'.

'Management support is nearly zero. I feel that management should be phoning up now and again and ask how things are going. I feel as though I have not got any support...'

(When his – understanding – boss, left) 'The personnel manager "basically wanted to get rid of me". The support dwindled away. I was easy meat. I used to go for (Lithium) injections in my lunch hours (and kept quiet about the Bipolar)'.

Summary

We found a lot of overlap in the categories of things that were unhelpful, and in the incidents. However, we felt that using a wider and more diverse set of categories was better than collapsing them, as it gave a better sense of the frustration people faced.

The categories, and related incidents, will be familiar to people with experience in the field. This must be a disappointment.

Certainly, while we were prepared to find unhelpful incidents we did not expect them to so outweigh the helpful incidents.

If pressed, we would feel comfortable in highlighting two, overlapping, categories that epitomise the problem:

- 1) discrimination, stigma, and harassment; and
- 2) lack of support/reasonable adjustment.

The Wish List

The wish list consisted of things that those people interviewed felt would be helpful in the workplace, particularly in relation to successful employment.

By 'successful employment' we mean people being able to do meaningful and rewarding jobs where they are able to 'be themselves' and not receive 'special treatment'. We mean employment where people are accepted as perhaps being different in some way but are not discriminated against because of this.

The Wish List was, by far, the most comprehensive and challenging set of responses we had.

It showed a dramatic shortfall in equality of opportunity and fair treatment.

It was useful, too, in adding 'flesh' to the bones of the previous two sections. For example, while need for/lack of support was a dominant and powerful category it was difficult to define. The comments on supportiveness made under the Wish List section helped to more clearly provide definition of just what people mean by support.

We identified ten categories of things that were helpful. Six of these cover different aspects of 'support' and help define what people mean when they talk about this topic. We were struck by how much these categories related simply to good management and good working conditions in the World of Work, and none of them seem extensive or unreasonable.

This led us, quickly, to the conclusion that it is very likely that in a good working environment with good working conditions people with bipolar conditions are likely to manage and engage effectively, and likely to make a strong contribution.

However, the converse will also be true. In a toxic working environment, or when faced with toxic managers, people with bipolar conditions may have their condition exacerbated.

This is a strong consideration for all employers as it brings a number of legislative issues to the fore ranging from Health and Safety through to discrimination and harassment.

The ten categories identified for/as the Wish List were:

- (1) Someone to talk to and provide support;
- (2) Mentor (advocacy);
- (3) Work related support;
- (4) Flexible working;
- (5) Education of Employers/public recognition;
- (6) Proper diagnosis and related professional support;
- (7) Support with employment and addressing inequalities;
- (8) Respectful employers who recognise and support people;
- (9) Disclosure;
- (10) Addressing Stigma.

(1) Someone to talk to and provide support (10)

The need for someone to 'talk to' was raised. This person needs to be someone that can be relied upon, and can be trusted. They should also be a member of staff. Only once was a counsellor raised, and this was not in keeping with the tenor of the other comments. Rather, it seemed more like the need was for a work colleague/s who was/were generally willing to listen and who understood the person and their needs. Sometimes this person was also considered as a 'go between' or 'broker'. That is, some who can '...could advise other people what they could do to help...'. Comments were made about the need for 'trust', being able to 'rely' on this person, and (this relationship) having no impact upon the person's job.

We need to be very careful to distinguish this from a 'professional friend' relationship. That is not the requirement. The requirement is for someone who demonstrates a real friendship and support.

'There also needs to be someone you can turn to as a friend, and it wouldn't affect you getting a job or keeping a job.'

'Someone you can trust who will listen to you, someone you can relate to, and monitor your well-being.'

(2) Mentor (6)

In terms of a professional relationship in the workplace mentoring was raised. This included an 'advocate' or 'counsellor' and the importance of 'independence' was raised in relation to trust and confidentiality. The crux seemed to be someone who would understand and support people with bipolar conditions and would support them. It was even raised as a line management issue and, indeed, it could be very strongly argued that this is a normal line management requirement.

'Perhaps a mentor, someone who can be aware that there could be a problem, because often I couldn't see the signs myself, and they might be able to step in earlier and say, perhaps, take a day off.'

'For me, if I had like a mentor, like we talked about with that person as my manager that would help me...someone I could discuss my problems with.'

(3) Work related support (7)

This category was a little mixed but seemed to focus on monitoring of workload, time management, and the need for respite/time away from work. Again, this seems very much like a normal, indeed obligatory, line management function.

'...to have workload checked regularly, and supportive contact when unwell.'

'It would have been good if they could have checked up with me once a day to check if I was doing alright. Often I felt like I was drowning and no-one would have noticed.'

'If there had been better coping mechanisms looking at problem areas and how to deal with them I might have stayed.'

(4) Flexible working (13)

This category was surprising. It was very odd to hear people relating the lack of flexible working practice and, at times, how people had been refused flexible working arrangements.

'Being allowed to go part-time/job share - I was refused this.'

Flexibility in working hours also related to being allowed to have time off for medical appointments, or to take medication, the option to move between full-time and part-time, and flexible working hours. It also related to greater flexibility in the benefits system, but, generally speaking, benefit issues were not high on the agenda for the people we interviewed.

'I'd like, when I'm not very well, to have time off work without being penalised for it.'

'There needs to be a better understanding and flexible approach to time off.'

'Flexible working hours are paramount.'

(5) Education of employers and public/recognition (18)

There was a strong sense among interviewees that both the public and employers were ignorant of the condition and its consequences. There was a strong perceived need for education of public and employers, and '...much higher recognition of Bipolar...'

There was a clearly stated need for more awareness and knowledge about the condition. Suggestions included greater press/media coverage exploring the issues; a higher level of education of employers; as well as understanding the links to mental health, legislation, discrimination, and disability.

'Personnel and other managers should be educated what bipolar is all about.'

'There is not so much increased knowledge about mental illness which is what is claimed'

'People are still incredibly ignorant of what mental health issues really means, especially to those close to the people involved.'

'Understanding by management and organisation. Close management and monitoring of professionalism. An understanding of mental health by management/the organisation.'

(6) Proper diagnosis and related professional support (19)

While we have given this category the label 'proper diagnosis' this is in relation to 'professional support'. It is important to note the people were not pressing for a label, nor

where they pressing for a medical diagnosis. What we are highlighting here was that people were noting the need for proper and appropriate support for those struggling with the condition.

What was raised was the need for - professional support from the mental health community and ranged from psychiatric support through to community support in the form of outreach.

'It would be useful, if you do declare that you have an illness, that you get to meet a person who is supportive, someone who is there and always there for you. Maybe an occupational nurse.'

'The main thing is correct and early diagnosis. If I had been correctly diagnosed then I would have been able to manage my illness.'

There were calls, also, for practical down-to-earth help in the form of on-line counselling, phone lines, and 'someone who can go to the employer...'

(7) Support with employment and addressing inequalities (13)

In this category people noted the need for a range of support from writing CVs, to identifying jobs, and filling out application forms. Employer advocacy was raised.

The importance of a good knowledge and understanding of both the condition and the persons needs/wants and working conditions were cited.

There was a strong sense in this category of people wanting to work, and even needing to work, coupled with a sense of frustration. There was frustration at the lack of adjustment in the workplace, and the lack of recognition.

'An employment advocate who can work out a package with the employer which is appropriate to me but is also agreeable to the employer and their patterns.'

'The importance of earning and of work for self-respect and self esteem...When you are out of work you are in the dark and you're going round and round, You need a ray of hope that you are worthy of earning money, you owe it to yourself to have your respect.'

'It is positive to stay in work but those with bipolar can not do run of the mill jobs. They need creative employment and unusual jobs.'

(8) Respectful employers who recognise and support people (10)

This was another rather mixed category. In the context of the incidents collected it was clear that employers did not respect people who were 'different'. There was lack of flexibility, in thinking, and in real terms. What people seemed to be asking for was a better understanding, underpinned by respect and support. This overlaps with better understanding and education, support, and flexible working, but we felt that it was important enough to be considered separately. After all, given the respect shown by

employers in relation to ethnic minorities, physically disabled, and sexual preference and religious groups the question arises: 'shouldn't the same level of respect be requested by people who behave differently?'

'Fix a monthly review to see how you are going, and is there anything stressing at work, and is affecting your health.'

'Insightful assessment of someone's ability to work and help to make sure people with BP are not shoved in to non-stressful and therefore non-rewarding work - and that affects the way people feel better about themselves.'

'I have chosen, as a graduate, to take a low stress job. When it comes to other forms of support there might be it might be different if I was in a more stressful job. I would say to people, and this sounds awful, but I would say to people don't tell your employers, if you can. It shouldn't be like that, but that's the way it is because you are going to miss out on opportunities if you are labelled - and you *are* labelled.' (see also disclosure, below)

(9) Disclosure (5)

There were mixed responses regarding disclosure. Overall, it seemed people would prefer to disclose as this would help others understand and would help gain support. However, people seemed nervous about disclosing and seemed to feel the risk of discrimination and harassment was too high in the current climate.

When people had disclosed successfully they seem to have benefited (with some dramatic exceptions). However, there was a need for help and advice on disclosure.

'I've always been very open about my condition otherwise people won't be able to understand, and it could cause problems.'

'I would say never go to a job without saying I am bipolar. I would always declare, and then they would take that on board and have it in the back of their minds should anything go wrong, to understand reasons or times when I would need to be absent.'

(10) Addressing Stigma (17)

Strongly linked to educating people about bipolar we found that this category highlighted the problem of stigma, prejudice and discrimination and the need to tackle this. This category highlighted how difficult it is for people to manage the condition when faced with stigma. It was highlighted on the wish list because it emerged here and does link to other parts of the wish list.

People seemed to be in agreement about the importance of tackling stigma, 'The biggest key is to de-stigmatise the whole mental health issue, generally' and that 'People with mental health issues to go out and address companies and others about their experiences - more of this should go on.'

Overall the level of stigmatisation, and the attendant problem/s, was well recognised by the interviewees:

'Once you are labelled mentally ill it's such a stigma for you.'

And

'Education of the people you work with is critical, perhaps more so people you work for (ie those above you)so that they don't see you as some kind of weirdo...'

And

'Most of us come to work and we are ashamed to tell people we have bipolar.'

And

'The problem is that with any company once people know that you have a mental illness people look at you so differently.'

People clearly felt unable to be open about it in the work place and this made them uneasy as well as making the condition more difficult to manage.

'It is absolutely out of the question that I would tell people here. If I was off sick I would put it down as "stress". I get my GP to do that too. If we need to take time off we should not have to lie about it.'

And

'If people could understand, talk to you, and realise that everybody is different. Just because you have bipolar you can join in. They don't ask you to join in.'

In terms of the actual resolution it seems that people would link this to education, support and disclosure. That is, tackle discrimination and stigma through education, work place support, and the opportunity to disclose safely.

Summary

The wish list seemed to produce the highest level of incidents in the form of things people would like to see being done, or changes made. This is in keeping with the pattern observed across the 'helpful' and 'unhelpful' sections.

Overall we could collapse the categories given above as follows:

Support. Here we note the need for:

- + Support in the workplace from friends, colleagues and management (which would include mentoring);
- + Professional support that ranges from good diagnosis and medical advice through to work-related and community support.

Employment. Here people noted (largely) what is good practice in employment terms:

- + Flexible working;
- + Fair, professional, properly trained and educated managers.

Discrimination. Tackling discrimination includes:

- + Educating employers and public;
- + Providing job seeking and job retention support;
- + Helping with and advising on disclosure;
- + Tackling stigma.

(iii) Case Studies.

Introduction:

Nine potential case studies were selected from the responses of the interviewees who took part in phase one of the research.

The criteria for selection (outlined above) was those cases in which 'at the time of decision-making appeared to be 'successful' cases - that is, people who are in work and have been successful in work, and/or those who were maintaining well-being whilst in work. The rationale behind this approach was that there is good evidence (backed up by sound theory) that highlighting what DOES work - success - leads to good learning and change'.

In the event seven participants were either prepared/or available to be interviewed as 'case studies'.

Case Study AA

Is a well-established and accomplished 45-year-old female who is employed, full-time, in a high profile 'media' type role.

In the initial interview she spoke about the support structures which helped her to remain in work and successful in a demanding role. She also outlined why she chose to openly discuss her Bipolar Disorder. A "lengthy and arduous" event was being planned so she decided to approach her employers about her concerns.

"I felt it better that they knew. It would have been problematic for me. I was allowed to be released. They were incredibly supportive. My line manager knows. My line manager is as supportive as he could be. He went along with my consultant's recommendations without questioning given his constraints (to the demands made on all involved in the project(s). Some colleagues know, people that I know and trust I have told them. My close friends are very understanding, they are aware of what I have gone through and are there for me if it should come up again. It's a support network that makes me feel I am not alone in coping should I become ill for specific episodes in the future".

Between the initial interview and the in-depth follow-up, issues arose for case study AA which were revealing of the benefits and disbenefits of disclosure and the

misunderstandings, and difficulties, which can arise whichever approach is taken. These issues were very much a 'live' (and dominant feature) at the time the in-depth interview was conducted.

Case Study AA was due to play a part in an overseas event. "My concerns were multi-faceted. It was going to be a concentrated tour. My illness began on a concentrated tour to Japan. I never got over the jet lag. I wasn't on medication and I didn't know if the American tour would be better. I didn't want to take the risk. I knew that (her employing organisation) has to take into consideration health issues. I wanted my consultant to be involved in advising my manager that it might result in my becoming ill. I thought about this at least a year before the tour. I raised it with my manager I also decided to disclose because there was a planned tour of Australia. I was seen by (the organisation's) doctor, a very brief summary was given to my manager (which didn't indicate the severity of what had happened but which gave him an indication of how to manage me and saying that "any touring that had to be done would have to take into consideration my illness". [The percentage of work touring overseas over the past five years had been around 1% - ie, therefore she was still (almost) fully functional].

Bipolar Disorder had been diagnosed 11.5 years ago after a "very, very, extreme incident when I came back from the Japan tour.

They thought it might be a one-off. I came back from the tour and I was imagining that people were listening to what I was saying. I wanted to go somewhere which I perceived to be safe. I went to a good friend's house and I thought that they were going to attack me. I jumped out of a first floor window and was saved because there was a conservatory below. I had very extensive injuries and was in a wheelchair. ["The 'organisation' had no idea"]. The medical profession thought it was an isolated mania incident. I became very depressed, then high, then Bipolar was diagnosed". [She has undertaken a number of tours, it is just the most extended ones which potentially cause problems]. "The whole essence of the touring environment – it is a much more intensive period of work, lots of travelling, more pressurised and tiring period, and you're away from home for an extended period".

She explained that ordinarily she can take the intensive work pressures in her stride. Overseas tours accounted for just one percent of her work over the previous five years. With extensive support from her husband, allied to the support she had received in work, she was able to remain "almost fully functional".

But the change, referred to above [between initial interview and in-depth Case Study Interview] then took place in her work position. Her account provided an insight into issues such as 'good practice' by a line manager; the problems such line managers can face in not being able to fully and openly disclose information about an employees Bipolar Disorder; issues around confidentiality; around bipolar and work; lack of full disclosure to colleagues, potential attitudes of/misunderstandings by colleagues (unaware of the bipolar); stigma around and ignorance of the realities of bipolar and/or mental illness etc.

Case Study AA: "Since I spoke to you something has blown up at work which has raised my illness and how it is managed at work and which led to an hour's meeting prior to our

summer break”. [She is part of a nine-person team who work very closely together as part of a much bigger integrated and creative team all of whom depend closely upon each other’s performance to achieve the desired results]. “An issue has arisen that they [the nine-member team she is part of] wanted to be made aware of how my illness impacts on me being treated differently. My manager has been very supportive to me but he has to tread a difficult line with the others. Part of the issue is the view (amongst one or two) that I am not always doing the same amount of work even though I am being paid the same.

[The issue which triggered the present problems:] “An uncle, who was very close, passed away. I took a day off work when I got the news. I should have been in work and someone had to go in to work instead of me. Some people felt that I should have been at work. I felt because of my illness that I didn’t want to work because of the chance that I might become stressed in work and ill. [She then went to the funeral at a time when she and her colleagues were due to take part in an event in London]. “I had to miss it. While I was away (herteam] had a meeting with my manager about their concerns. I had told them that I had a mental illness. I decided to tell a lot when I wasn’t going to do the American tour. The main issue for my colleagues was if I could be more open about why I had to take time off and if it could be managed so that they weren’t doing my work for me. This has caused me more upset than anything. It’s not resolved yet and it’s certainly still on my mind. What it raises with me is that I have gone in to work thinking of suicide all of the time and no-one has known all this time and yet when I have taken one day off all this has happened. I have not been ill this year. Last year [with the help and support of her husband] when I was threatening to go high I managed by taking time off work and extra medication – if there is a time when I am going high I manage by taking time off work. There are one or two people in my section who don’t understand mental illness, they have no concept when I say about being depressed. I didn’t understand mental illness until I had it. [Because of the effect the issues were having on her] “I wanted something to happen before the summer break. I had a very upsetting phone conversation with (the most senior colleague in her section – who is not her line manager) ... who said he had no idea why (she had been acting the way she had/taking time off etc). It was extremely upsetting. I sent him an e-mail afterwards which was very cutting and this was read out to the section meeting. He said in the phone conversation that I had ‘a delicate constitution’, I made it clear I was very upset and said if the section wanted to know how I cope then after the suicide attempt, and a week in hospital, I came back to work saying that I had had flu.

[Another issue which had impacted during this period]. While the [whole creative team] was in America there was a member who went but who didn’t want to do the tour. He was very depressed and committed suicide. He was only in his early thirties. Everyone in the (creative organisation on tour) had to deal with this whole thing while they were abroad. It is like an extended family. Some people couldn’t take part in the (events) afterwards they were so traumatised. What I find staggering is how little he comes up in conversation. [The tour was in February this year].

At the time of the interview she and her colleagues were on ‘summer break’. After the break a meeting had been planned between her/her line manager/ the senior section colleague. There would then be a full meeting of the section.

[How she intends to approach the meetings, now with her manager/senior section colleague and then with all of her section colleagues].

I will be absolutely fine. He (line manager who she asked to see before the summer break) could see that I was totally lucid. I am very articulate in putting my views across. My (senior section colleague) is someone I have respected for 20 years and someone I thought was friend. There was absolutely no excuse for the phone call he made. I arranged the meeting with my manager, and spoke with (the senior section colleague) briefly. When we go back I am going to have that open and frank meeting with him. It seems difficult with some people in the section. I think people will be absolutely fine. The funeral happened at the end of a very busy period of work and people were exhausted it was enough to kindle up a tinder box. My manager said that one of the things that came up in the meeting (of her section) was that when I was off it seemed to be when there was a period of busy work. I said it was because I didn't want to become high. [During the periods off she pays, her self, for a 'deputy' to do her work for her]. My manager said you are disabled (and that she shouldn't be paying for freelance cover) and some arrangement should be made. I need to talk to personnel because I may be on slightly dangerous ground but if that would make it easier for people to accept then maybe that might make it easier. Human Resources and personnel have no idea that I have bipolar. They had no need to because up until the tour I have never needed to have time off. But then again I was off the tour and still being paid so presumably my manager would have had to clear that with somebody.

My manager has been very understanding. As soon as he received the consultant's letter there was never any question that I would do the tour. Here is someone who I feel is a manager and has been very supportive to me. It was a very good meeting I had with him he is a very good listener and he is thinking of how we can work around the issues, of strategies that could be used. There was universal praise for him over the way he handled the suicide which happened during the tour. He offered to fly somebody home. He couldn't have done more

The possibility was discussed of her line manager taking part as one of the Employer Interview Studies. Case Study AA said she would discuss what she thought about this with her husband, and contact the Research Project Manager Paul Starling. In the event she rang two weeks later to say that she felt that because her line manager was likely to be very busy once the break was over she felt it was probably best not to ask him to be interviewed.

Conclusions

AA with close support from her partner took clear steps to forestall possible problems following her experience of a previous extended tour overseas. Her direct employer (line manager), knowing about her Bipolar has played a key role in helping her to maintain an effective role (and her well-being) in work. But stigma, misunderstanding, and ignorance around mental health issues, allied to the fact that she has not been as open with her other colleagues as she has with her line manager has raised difficulties for her, her line manager, the senior figure in her section, and for the section members as a whole. Her case points up the difficulties of non-disclosure, partial, and full disclosure. It highlights the importance of supportive employer attitudes, the ambivalent positions that 'confidentiality' can create, and the difficulties such things can cause for the employer which, in turn, impacts on the employee with Bipolar and those colleagues around her/him.

Case study MF:

MF is a male in his forties who has been running his own business with a partner for the past ten years. He had a serious episode in the late 1990s which resulted in him being admitted as an in-patient. Despite this he maintained the business with his partner. He felt that while his episode had a bearing on customers, because it was obvious to them that he was ill, they were understanding. However, a number of employees left the business as a consequence.

He says that when employed, and 'under pressure' he felt unable to mention it. It was as if he 'didn't have, and had never had', any illness. He described the sector in which he worked as 'an aggressive management culture' and this may have contributed. However, he also notes that he has had other jobs in the past and has never had the experience of being supported by employers. In particular, he never had anybody to talk to in the workplace other than his current colleague.

He feels that a key factor in his retaining the business while he was ill, and subsequently making a success of it, is that he owns the business which means simply that nobody could sack him or make a decision on the future of the business. It is a Limited Company originally with him as sole director, and a friend as Company Secretary. This friend, NJ, has since been appointed as a director but holds only a minority shareholding. Case Study MFMF feels that such control is important.

MF was ill for around 18 months, following the break up with his long term partner, and was admitted to hospital six times during this period. The maximum stay was about six weeks and each time he would leave hospital feeling better and go straight back to the business. During this time NJ was very understanding, even when MF was very ill and could hardly talk. NJ believes his wife has Borderline Personality Disorder and he has learnt to be understanding and patient in dealing with this, and that this may have helped in his acceptance of MF's illness.

During the time MF was in hospital NJ carried on with the business seeing clients and doing administration work. NJ also visited him in hospital and kept him informed about the business. MF also tells how, while he was a hospital in-patient, he would put on a suit in the morning go and do a seminar for clients and return to the hospital in the evening.

MF says he felt suicidal much of the time and, once, he admitted this to a friend, who phoned the office. A few minutes later an ambulance called his secretary to ask for directions as the friend had called 999. While in hospital he was asked how he intended to commit suicide. He said he would drive to the quarry and jump off. He did actually carry out that 'drive', one morning, but didn't go through with it. However, when he was feeling better and was back at work a few months later he had a letter from DVLA telling him his license had been revoked. The hospital had informed them of his suicidal tendencies and they decided to take his licence from him after he had recovered. "It took nine months of fighting before I got my license back and it was, understandably, a difficult time". It was also an event which potentially threatened (and, at the least, made it difficult for) the business.

When MF started the business and became ill his parents stepped in to help. Later they felt they had to withdraw because the demands were too high and they found it stressful.

“Fortunately this coincided with a time when I was making one of my many recoveries”, MF recalls. He was then able to take the reins up again.

During one of his ‘well periods’ MF recruited an administrator who, although very quiet, understood his frequent hospital admissions. She stayed with the company for several years and was very good at keeping busy during very quiet periods. He thinks her understanding was partly due to the fact she had a minor disability. Another factor MF believes helped is that both he and NJ were open and honest with clients who were made aware he was suffering from depression. He remembers that during the period when unwell but out of hospital, he saw clients and they were all kind and understanding. They were sympathetic to his situation and still followed his advice even though his thought processes were slower than usual, he says.

Following his last admission to hospital, some eight years ago, MF was referred to an “excellent” psychiatrist who helped him break the cycle of hospital stays, followed by recovery, followed by a further hospital stay. Since then he reports being “very well, apart from a couple of minor wobbles, and the business has gone from strength to strength’. There are seven people in the business now and all are aware of the problems he had in the past and accept this fully.

The business has since employed two young men who, separately, went on to have symptoms of schizophrenia. In one case, ironically, the individual attempted to take MF to an industrial tribunal for disability discrimination, only to withdraw his claim.

Conclusions:

MF notes particular forms of support. First, his parents were supportive and understanding. Second, his colleague, NJ, provided both moral and pragmatic support, including helping to manage the business. Third, (and eventually) he had excellent input from a psychiatrist who helped him break the cycle.

There is an element of disclosure. MF was open and honest with his clients and with all employees about his illness. In effect, he has gone for complete and total disclosure and this has had a positive outcome.

Perhaps most importantly MF notes the importance of control. He has total control of his business. Despite any stresses and difficulties MF notes that no one can sack him or make a decision without his knowledge about the future of the business. This element of control is a strongly identified factor in relation to mental health at work, although there is a strong reluctance to recognise this in some quarters.

Case Study AC:

Is a 57-year-old female. A former civil servant, she was “sectioned a couple of times” and realised that she “could no longer cope with that sort of work”.

She started with the civil service as a clerical assistant. “The first day I worked there I realised I had made a mistake”. She had previously worked in a hospital environment which was “friendly, understanding and compassionate”. Despite the contrast and her reservations she decided to “stick it out”. “I said to myself I would give it six months

because we had been brought up to believe you have to work for anything you want in life. But I could just see my self sitting there, there was like a flat feeling working in the revenue. People don't like the taxman, and unlike the hospital, I didn't like to work there"

She worked as a clerical assistant for five years and was then asked to consider a higher grade. "They suggested I tried the tax officer entry exam. I passed. It was two years training and I learned as I worked. I coped with that. One taxpayer rang and said I was too kind to be a taxman so my boss suggested I went to work in the welfare department".

She then experienced her 'first episode', as she saw it, and was admitted to the St. Cadoc's Psychiatric Unit. But it was not diagnosed as Bipolar Disorder.

"My bipolar, I now know, goes back 31 years. My mother was ill with terminal cancer in 1975-76, she died in April 1976. Looking back my mother, even though she was ill her self, was concerned about me. After her death I was admitted to Heath Hospital psychiatric ward (for a month), but it wasn't a full recovery".

She continued, spasmodically to become ill. "In August 1997 I was working in the Cardiff Royal Infirmary and things just went wrong. All I could remember was ending up in the Heath Hospital for 4-5 months, heavily sedated.

She believes that the loss of her mother was the major trigger point for what she now knows is Bipolar Disorder. "My mother came from London and she lost contact with her family. It was a big wrench. My mother was the mainstay. I was 26-27 and afterwards the GP said he felt it had been a big blow, he put my illness down as anxiety and depression.

"I had three what I now know were episodes while I was in the civil service. They said I had had too much sick leave – they gave me early retirement. The illness crept upon you. You can't say that one day you're fine and the next I was ill, it just crept upon you. All I can remember was being in hospital. I had 1200 cases at the Inland Revenue, I coped. Writing to solicitors, families of the deceased, debt cases, it wasn't the most cheerful of subjects. I had these episodes and I found myself in hospital. I worked at the Revenue for ten years. The first five years were fine, but then I had these episodes, 3-4 over the period, when I would end up in hospital for weeks rather than months (say six weeks at a time). Then I would be home for a while.

"There was no support. I remember one of the girls coming to the hospital with flowers, but there was nothing from the Revenue. Once you were back in the office you were expected to carry on as normal. You were just on sick leave. There would be a "nice to see you" from the girls but that was it. One Inspector asked 'are you happy in your work?', that was it. The nature of my illness was never openly talked about. In the Civil Service if you were ill you stayed home. I found it fairly impersonal. When I was working in the hospital I had the understanding and compassion but not in the civil service.

"After the illnesses I went to see the District Inspector. I said that people were having 2-3 maternity leaves and then coming back, and why couldn't I have leave for illness. He said if someone's pregnant they should leave the job and stay at home with the children. They gave me early retirement without a civil service doctor seeing me. There was no support. There was a welfare officer when they retired me I asked him to ring me and I said I felt I was being unfairly treated that I had still got to pay my way at home on this tiny pension but there was no support.

She left the civil service 21 yrs ago. "I was 36 and nobody bothered to consider my age". It was to be a further ten years before Bipolar Disorder was to be diagnosed. "I had never heard the expression before. I never knew what the diagnosis was from the hospital (when they 'retired' her). No-one bothered to consider my age. This mental illness has caused me to lose an awful lot in life because I had a good career in the civil service. If it happened now I would have more support. There would, likely, be a proper diagnosis and with the medication and support from the community nurse etc., I would still be in the civil service".

After she left the civil service she was out of work for 10 years. The diagnosis changed her life, she says.

"Eleven years ago I had an admission to St Cadoc's for 28 days under section. When the 28 days were up the doctor said I see from your notes you are back and forth. He wanted to monitor me on new tablets and I agreed to stay for 6 weeks. I had the freedom to go in to the village. I came home after 11 weeks. The community support worker came and has been coming every week for eleven years. There was an advert in the local newsagent about working in the local pub (for 4 hours a week). I talked with my community support worker and with my aunt and I gave the landlady a ring. '*****', the landlady, knew me and said come and have a chat. I went but the way I was dressed and I was not very confident, she told me later that if she hadn't known me she wouldn't have given me the job ... I skipped up the road I was really pleased when she said I could work there. For the first 3-4 months I wasn't very good, but she said she was determined that I would do it. She gave me a chance and a lot of support. She cares and shows me that".

She has now worked for ten years at this local family pub - because of the support of the landlady. "She calls them my ups and downs'. I have gone from not being able to do anything at all to running the pub when there's no-one else there, and training people".

"When I first went there my confidence had gone. She [the landlady] could remember me before I was ill. She was interested in me and was determined that I would get back to how I was before I was ill. She was very patient and supportive. Sometimes the clothes I wore made me look a bit mental, she would give me help and advice about my hair and appearance. She really boosted my confidence. She's always had faith in me. They trust me with the pub and the money when they're not there. They've always given me praise and that boosted my morale. I've been good for the job and the job's been good for me. I cope. It pays the rent, gets me out socially, and it's been very therapeutic".

"I'm quite open about my illness in work. If people ask me how did I come to be here I tell them. Before, I would walk around with my head held down thinking that everyone knew that I had been in a mental hospital. I've gone from not being dressed very good, or confident, but with the support of my boss and the community nurse I now train new staff and being able to deal with anyone who walks in the door. On Wednesdays my boss and her husband go to the cash-and-carry and I look after everything. There has been a vast improvement. In fact I would say I am back to my old self. I would recommend my bosses, I am really thankful, they broke the vicious cycle. I'm working 15 hours a week now, and with the medication I am able to return to the mainstream of life".

Conclusions:

Read in conjunction with Employer Interview 1 this Case Study highlights key conditions which employers may/could/ought(?) to aspire to. It is an object lesson in creating the

conditions where someone who was profoundly undermined by Bipolar Disorder, and in the process disconnected from social contact, can become a (much more fully) functioning social being who is able to work and take control back of her life and decisions. The real therapeutic change came about from the level of belief, and non-judgemental support from her employer, from her work colleagues, and from members of the wider local community who could remember her before she 'became ill' and who were determined to help her re-integrate. It is a story which provides insights in to the conditions, management style, attitude, mutual respect and support, which can provide a healthy working environment.

Case study MM: (completed jointly with MF)

MM is a middle-aged male who has had a continuous career for over twenty years. He has been in his current job for over three years. He is a professional, working in the public sector.

Some years ago MM had what he calls a 'mental health crisis', resulting in the loss of his job, and was unable to work for much of that year. During this period he survived on what savings he had. At the time of the health crisis MM was diagnosed with Bipolar Disorder. MM subsequently found alternative employment and has been in continuous employment since then. He has not disclosed to his employer and this creates some difficulties which are discussed below.

While MM enjoys his work he feels that Bipolar Disorder places constraints on his working life. To better manage these constraints he moved away from positions that involved a lot of management responsibilities.

In relation to working life MM highlights that he works like everybody else and does not want to be treated 'differently'. He appreciates, and enjoys, a team setting where there is respect for people's beliefs and attitudes and an easy, benign, humour. He feels that the structure provided by work is helpful, as are clear roles and responsibilities. MM acknowledges that he works in a stressful environment, and that work can always be stressful at times. In relation to support, he notes that he looks to this from friends who he has shared his diagnosis with, and his family who were around at the time of his health crisis and have been supportive since then. He has also had discussions with medical practitioners and MM feels that the advice and information provided has been mostly supportive and helpful.

Disclosure was an important consideration raised by MM. As noted above MM hasn't disclosed in the workplace. This is unsurprising given he once lost a job. In addition, he notes the general lack of awareness and understanding of Bipolar Disorder in the workplace.

MM has gone to considerable lengths to find out more about disclosure, including seeking legal advice. However, he found that the legal advisor he spoke with was reluctant or unable to discuss the issues with relating to discrimination and disclosure. He also found a lack of support to: a) help with making his decision; and b) to support him if he did disclose. A major consideration has been the lack of information about the likely process

that his organisation would follow and about the possible outcomes. Consequently, he feels that the risk of making an uninformed decision about disclosure is high.

Not disclosing does create recognisable difficulties for MM in the workplace. He talks about having to 'second guess' at times because he needs to take time off, for example to undergo regular health checks. However, at times he has made this look like 'normal time out'. Put another way, MM often takes his own time off as 'down time' to manage his mental health. In addition to this, there is added pressure on MM as he feels he is unable to be 'open' about his Bipolar Disorder in the workplace.

Conclusions

MM has taken proactive steps to manage his Bipolar Disorder in the workplace which include:

- Giving thought to career options and the types of positions he believes would be suitable
- Seeking support when he needs it. This includes: Discussions with friends and family members; Discussions with medical practitioners; Taking time out to manage his mental health when he needs it.

MM also notes the constraints placed on him by non-disclosure. He clearly highlights the risk of disclosure and the absence of good advice, clear management strategies, and support. MM makes an important point that it is not enough to have only one of these things. That is, advice in the absence of strategies and support can never be good advice. Similarly, an unsupported strategy is no strategy for disclosure. In relation to this he also raises a key issue of lack of understanding and awareness about bipolar disorder in the World of Work.

Case study AB

AB is a middle aged male working in the voluntary sector. He has been in work for a substantial period of time and was diagnosed less than five years ago. He has had a substantial amount of time off work over the last few years and has disclosed in the workplace.

AB noted the importance of support from work colleagues and 'friends in the field' when it comes to staying in work. He explained how supportive work colleagues can help him manage his behaviours and facilitate his contribution in work. He articulated supportive friends as those who understand. In relation to this he also noted how both formal and informal structures are important to helping him stay in work.

AB related his historic experience with a lack of formal structures. He explained how after being severely unwell he had taken a drop in grade at work and, consequently, other staff did not know if he was 'one of us or one of them'. The lack of formal structures to provide support meant that other staff members did not know how to relate to him and became uncomfortable with him. They began to see him as 'one of them' and the only course of action available was for him to change jobs.

Yet, while his current employer, similarly, has no policies or procedures to provide support - there is support from work colleagues. However, the lack of policies and procedures also means that he is vulnerable to changes in working practice/conditions that can impact directly on his well being. In relation to this last point AB highlighted how important it is to have supportive line management and how good line management can provide a 'buffer' against adverse working conditions.

Particular working conditions that he cited as important included flexible working hours, and the opportunity to work part-time. Being able to work independently, and also being closely managed at times in terms of clear goals and targets, which provide good boundaries.

The opportunity to exercise creativity in work was seen as important, by AB, in relation to being able to cope with work. He pointed out that one symptom of Bipolar Disorder is creativity whilst on a high. He talked about having lots of ideas and the importance of being able to articulate these ideas and try them out. The restriction of this creativity is 'frustrating'. As a pattern he noted how repetition and routine suit him when he is 'down', but become frustrating and mundane when he is 'up'. This frustration can be stressful and that can lead to illness.

It is important to have a creative outlet and recognition that his ideas are important and valued. He noted that people with Bipolar Disorder can be good employees when they have an outlet for their creativity. Here he noted, also, that creativity doesn't have to manifest, necessarily, in the workplace and gave examples of 'life lines' provided by activities outside of work.

Conclusions:

AB highlights the key points as:

- Having good support in place in terms of formal and informal structures. Informal structures include supportive work colleagues and/or friends in the field he can discuss things with.
- Having good quality line management, which includes the setting of goals and targets and professional support.
- Being allowed independence and flexibility in terms of working hours.
- A balance between having his ideas and creativity used and valued when he is 'up', and being provided with routine and repetition when he is 'down'; and having an outlet for his creativity either in work or outside of work.

Case Study KG

Is a 41 year old female who suffered with depression since she was in her early 20's. By 1997 she suffered 'a major breakdown' but was mis-diagnosed with 'clinical depression'. It wasn't until four years ago (2003) that she was, eventually, diagnosed with bipolar disorder in 2003.

She has had 3 jobs. The first as a checkout operator. Her employer was unaware of problems, but KG found it very tough coping with mood changes.

Her second post was as a classroom assistant. She was diagnosed with bipolar disorder during this time, and informed her employer. She says that the Head Teacher was very

supportive. It is difficult to assess the exact level of help, because she eventually married the Head Teacher! However, she recalls that she found her co-workers to be very supportive and saw a long term future in this role.

Her third job is working with/'for' her husband. [See Employer Interview Three] as a joint caretaker.

Her husband was offered early retirement, and accepted, in 2005. They moved to Wales to take up work as joint caretakers for a private family looking after a 50 apartment building. The work includes cleaning, repairs, security of building, and general maintenance. She says that she is very happy with this 'work change' as it allows her to work at her own pace and the partnership with her husband means she can manage her condition and mask the effects of bipolar disorder. For example, she says, if she is tired, she is able to rest. When she is well, she can work effectively, knowing she is fully supported.

Conclusions:

In this example Case Study KG made a conscious decision that it was 'healthier' to be open about her 'condition'. The attitudes of her employer (who had had previous experience of dealing with staff with mental illness), and the support of her colleagues following her disclosure were helpful in making the adjustments which allowed her to remain functional in the work she was doing. Their decision (Headteacher and Case Study, who had since married) to seek a different balance between 'work' and 'life' and to do joint (and less stressful) work allowed greater flexibility which, in turn, allows KG to better manage her 'condition'. Her 'employer', of course, is deeply empathetic to matching his 'employee's' needs to the work required.

Case Study XL

Is a 50-year-old female who has worked as a chef in a small family business for 7 years. She was diagnosed with bipolar disorder 5 years ago, following a breakdown. She was asked by her employer to return to work earlier than she would have liked, but agreed to return. She is now glad that she did because, she says, it helped the recovery process. Her employer knew her before her diagnosis and was very supportive. All of the staff were informed and her employer agreed to flexible working hours. Her manager has suffered with depression for many years, so had an understanding of XL's problems.

Four years ago she asked to change her work pattern in order to do part time hours. She did this not because of the effects of bipolar disorder, but because of the discovery of a natural ('new') talent.

She had attended an "Art as Therapy" course to help her manage her condition. She had never painted or sculpted, but found that she was a natural artist. She was eventually accepted on to a B.A.(Hons) Arts course and is now in her final year. She has recently won a prestigious Arts Award and the organisation involved is committed to giving exposure to her work, promoting her work, and supporting her to develop her skills. It is very likely that she will become a full time artist, with the emphasis on modern sculpture.

Her employer continues to be supportive. In the Summer, XL works up to 50 hours a week, and then works around 12-15 hours per week during term time.

She believes that getting the right medication is the key to her success. She says she feels able to channel her illness as a creative tool, and says that all her work is informed by bipolar disorder.

Conclusions:

The attitude and approach taken by the employer, in this case, is revealing. His early intervention encouraging her to return to work after 'breakdown', his (and their colleagues) support, his attitude towards a flexible package of working, created the conditions for XL to return, re-integrate, and work, at a pace which was healthy. Her decision to find a balance between work and life released her. Her employer's own experience of 'depression' informed his attitudes and helped create the conditions where XL can function successfully both in work, and beyond.

(iv) Employer Interviews.

It is both indicative of issues defined above, but also of the timescale in which we completed this research, that there were not more employers willing, able, and/or available to take part in being interviewed as part of this project.

Nevertheless the interviews that were conducted, when read in conjunction with their linked Case Studies, provide important insights for the wider report.

Employer Interview 1: (Employer of Case Study AC).

She runs a busy country pub/restaurant. Employed Case Study Participant AC whom she had known for many years but who had lost touch both with her and with the area.

"I knew AC for lots of years before her illness and I hadn't seen her for lots of years though I had heard that she had had problems. I put a notice up locally saying I was looking for (staff) help. She rang and I knew she wasn't well. I asked her to come in so we could have a chat. She did and I could see she was very ill from the rocking and the clothes that she wore. I talked her through the job. She said "I don't think I'll be able to do the job" and I said "I'll be the judge of that ****". I got her to do quiet shifts to start with because I knew that she wouldn't be able to cope if it was busy. It was two years before we really saw a lot of difference. She had problems pulling the pints properly. I would say to her you change the barrels ****, so that she would start to build up her confidence, and then say I'll just be up the stairs if you need me. If she made a mistake I would say "you can do it, you've just messed up a bit now". It kept going like that - for two years. I would say to her hey **** people are coming in and they haven't even had a pint yet and they're feeling that they're drunk (because of her rocking), she would chuckle, and at other times I would say they're going to be drunk before they've even started. ****'s clothes sense was something as well. She would wear doc martin's with ankle socks and weird clothes. After two years I said to

her, one day, I'm going to Cardiff on Wednesday shopping let's get rid of those doc martin's, let's dress you up a bit . We bought her some nice shoes, and a skirt and we had a meal. Generally it started giving her her self confidence back. She would say "I can't really do this" but bit by bit there was a change, **** changed her attitude towards her dress. I could see the change, she was having discussions with customers, where she wouldn't before. She had her hair done. It's been a long period of time but we laugh about it now when I say "you're more ..whatsit .. than I am". The changes? Change of clothing, she's stopped rocking. There's all sorts of gentle ways of going about it. Now she does god knows how many shifts. It's not a problem. Now and again she does slip back and I say "come on sit down here with me, we have a sit down and she says 'oh, I feel better now'".

Employer's experience of providing support to help 'AC' stay in work. Why did she provide the support? How long has it been provided for?

"I have known her for many years. I'm always willing to give a person help. I've helped others – someone who couldn't write. When he was working there as part of the bar staff I could see he couldn't write even though he hadn't said anything during the interview. I said there are ways around it. I said that I'd need to tell the other staff and we'd find ways. If anyone came in with a food order I said go and tell the other staff, they can take the order while you take over serving drinks. He was with me for three years. If I can help someone I won't turn my back". 'AC' has been working with her employer, now, for eleven years.

What is, helpful and supportive in the workplace. What support did/does she provide that helps 'AC' stay in work. Who provides this support? Why was this helpful.

"I give her 101% backing. Sometimes I have people who would not be kind, I would step in, then. There are lots of the regulars who she went to school with and a lot of support from them. A lot of the regulars have known **** for years and they give her lots of support. There was a time when some of them came in for their drinks. **** made five mistakes pouring the drinks. One complained and I said "If you've got a problem I'll just have to get rid of her then", and he said "don't you dare do that" and I then said "well there you are then". I explained what she has been through for years. She now has a joke with them and says "Oh God what was I like". The fact that she is in the community where she came from is helpful. Six out of ten are non-regulars I would step in if there are any problems. I knew she could do it. I could remember **** when she was very slim and wore lovely dresses and then she put on all this weight I didn't recognise her. She is absolutely marvellous now it's very rare when things are not going too well. The rest of the staff are very helpful, they think that she's absolutely wonderful, she can't do anything wrong with the staff she gets lots of support and they love her to bits".

What sort of things are not helpful to her as an employer when providing support for 'AC' to stay in work. Why is this not helpful.

"To be honest it was the beginning. Day one when she came across to have the chat I knew it wasn't going to be easy. She was spaced out. The rocking when I was talking to her. The way she dressed. It took a long time. It's not just a pub it's also a restaurant. People would come in and you could see 'the look'. It's a country pub and it gets very busy and any outsider ... well .. I was always thinking about that, but I would say No, I don't care, anyone could snap. I would always be 101% and if anyone said anything I would be there. The way she dressed, the rocking, the complaints she wouldn't have lasted in many

places and there are a lot of places that wouldn't have taken her, I don't think many people would have the patience to keep her on board. That first call when I got it I said now come straight over now, other places they probably wouldn't have said that and she would have lost confidence to come for an interview. She came over and it took me back a bit. If I was someone else I don't think they would have taken her on because of the way she was with the rocking and spaced out. I know this sort of industry – they would have thought No!”.

Is there any sort of support she would like to provide but don't/can't provide, but which she thinks would be helpful.

She would like attitudes to change. “If you heard the stories that I have heard about ****’s illness (from other people)”. One heard that **** had come in for an interview and she said about something that happened involving a knife in a street. She said you must be bloody mad taking her on. What if she turns again. I said something like that could happen to anyone. And I said ‘you were depressed for two years, after you’d had a child quite late, and I took you on’. I have taken on three people with ‘problems’. **** was the hardest but I was trying to bring her back. I believe that everybody deserves a chance. If they can be helped they should be. If you can help somebody give them that chance. What is bloody normal? With customers I always get annoyed when anyone says ‘those bloody people’. I hate seeing people when they are flat, or flattened. They can come back in to things, and it can happen. If I had more time I would like to do more, volunteer, I would like time to help people”.

Employer Interview 2_ (Employer of Case Study XL).

Says that XL was initially engaged because she was a very good chef .

Prior to her breakdown, they had ‘developed a good working relationship’.

“When she had a breakdown I was able to help her because I had also suffered a breakdown years ago and I understood what she was going through. I also realised that she could easily become housebound , so I forced her back to work against her will.

“This was done as a friend and Rita has thanked me many times for this.

“Most of my staff are aware of my depression, so when we discussed Rita’s bipolar disorder , they were supportive and understanding.

“Because of the nature of our work, I was able to be flexible regarding the hours of work, and (XL) has always been willing to work extra hours wherever necessary, so it is a good arrangement.

“Generally, (XL) is a bubbly , energetic person , though I know when she is not well and we talk openly about her problems.

“(XL) has surprised us all with her artistic talent and I am proud of the way in which she has developed and blossomed. I like to think I had a small hand in helping her to recover and to gain the confidence to achieve her goals”.

Employer Interview 3 (Employer of Case Study KG).

Employer 3 has gone from being KG's employer, to her husband and then again her employer/partner.

He was KG's Head Teacher when she worked as a classroom assistant. KG was open about her mood swings from the outset. This was a deliberate decision as she had found "masking" her condition whilst working in a previous job as a checkout operator to be extremely difficult. The teaching staff reacted well to this honesty. Employer 3 had no direct experience of bipolar disorder or depression, though he had managed teachers who had developed mental illness in the past. This helped to inform him about depression. He initially kept a close watch on Julie's work - in order to support her.

It is difficult for Employer 3 to be completely objective, because their relationship began during the early months of her employment. However, he believes he would have been just as supportive whether this had happened or not

They now work together as joint caretakers and this allows them both to 'play to their strengths'. The job is varied, and there are few deadlines to meet. This means that KG can "take a back seat" when she feels unwell. Employer 3 is totally supportive of this, as he knows that Julie is conscientious and will play a full part in the work when she is well.

This is effectively a job share. Although Employer 3 is not the *actual* employer, in effect, he *has* taken over the role. It is an ideal situation, as Julie knows she is fully supported and so there is little pressure.

Employer 3 enjoys the job, as it has none of the pressures of being a Head Teacher, while KG likes the challenge of a varied job and sees it as less demanding than working as a classroom assistant.

7. Summary.

We set out to establish the 'services', and forms of support, those with Bipolar Disorder consider to be helpful and effective to help them retain jobs/work, based upon their personal experience, perceptions, expectations. We also aimed to determine what employers consider feasible in terms of job retention for those with Bipolar Disorder based on their personal experience, perceptions and expectations. The aim was to gather insights directly from those who know best what it is to live with Bipolar Disorder – those who have been diagnosed with what used to be known as manic depression. Three hundred and sixty invitations to take part were sent out to members of MDF The Bipolar Organisation Cymru. Almost a fifth (70 members) volunteered to participate. In the event, 53 were eventually interviewed. The findings of what participants found 'helpful', 'unhelpful' in work situations (regarding bipolar disorder, attitudes, disclosure etc) were all categorised and databased using what is known in (and accepted as a robust model by) the academic community as the Critical Incident Technique (CIT). Participants were also asked to define what they would have hoped for (what we defined as a - 'wish list') in a work situation. These findings were also databased.

The CIT technique proved to be a powerful way of accessing peoples' experiences while at the same time achieving 'necessary objectivity'. We found people willing and able to relate their experiences within the defined categories. We also found that interviewers were able to categorise incidents simply and effectively.

What shocked us was the small number of helpful incidents compared to the large number of unhelpful incidents and the even larger number of 'wish list' incidents. We said that this was disappointing; disappointing because we had hoped that the world of work was providing a greater level of perceived support than it appears to be here.

What we found was a consistent and emergent theme around support. We could readily summarise all we found under this single heading which could then be broken down into types of support and, for want of a better way of putting it, types of 'anti-support'. However, we acknowledge that support is complex and varies across individuals. Nonetheless, the clear way in which interviewees articulated the impact support had made to them demonstrates this as a key area.

We also found that support was multi-tiered. There is informal support generally: family, friends, the community. There is actual, recognisable, informal support: friends in the workplace; team support; line management. And there is formal support structure (which equate to well recognised good working practice). The latter includes: flexible working; good HR policies that are followed properly; best practice line management; equal opportunities; and so on.

Undoubtedly, the biggest problem faced by people with a bipolar condition was disclosure. Peoples' experiences varied from disclosure having a profound and substantial change for the better to disclosure resulting in even further discrimination to the point of dismissal. Yet without disclosure there is no mechanism for people to either access or develop support. We note that in terms of disclosure the issue is clouded by diagnosis. Many people with a bipolar condition will never be diagnosed. Some people with the condition actively decide not to seek diagnosis. Indeed, the only route to 'diagnosis' may require hospitalisation and the imposition of the medical model. This is a complex argument and is raised here to highlight the importance of our work. That is, how many people who have actively chosen to self-manage their condition and have actively decided not to seek

diagnosis are affected by the difficulties we have reported here? (While we cannot know the answer to this we note that it is now generally assumed that up to 30% of the population of people affected by schizophrenia may be undiagnosed and in remunerated employment.)

The case studies provided us with a deep insight into the lives of people while at work. They provided powerful examples of just how well people can manage when the support is available, and, in contrast, just how bad things get when the support is either stripped away or not available. They also provided uncomfortable insights into just how wide and deep discrimination and stigma is in the workplace.

The case studies support the findings of the CIT interviews and add a level of detail which demonstrates the impact on peoples' lives. We are at pains to highlight an important consideration here. The impact is not 'caused' by having a bipolar condition. If it was then all people with a bipolar condition would be similarly affected, and clearly they are not. The impact is 'caused' by the level of 'anti-support' in the workplace. The question is, 'how do we make changes in the work place to overcome this?'

This last point is important . Bear in mind that people do not want to be treated differently, or to have special conditions. They simply want to be treated equally, and fairly, and with consideration and support that empowers them to function.

We had difficulty accessing employers for interviews. In retrospect this comes as no surprise. That is, hearing what the interviewees had to say about the discrimination and stigmatisation we suspect that it must be a particularly difficult for employers to come to terms with. Unfortunately, the employers interviewed all had prior relationships with the employee. This makes it difficult to get an overview of how employers perceive the bipolar condition and how they can provide support. However, it does reinforce what we already know from the literature. Namely, that employers/managers with personal experience of mental health conditions, whether themselves or through someone close to them, tend to be more understanding and able to provide appropriate support.

The employer interviews show us how the employers, and managers, were able to accept the condition and not be unduly challenged or threatened by it.

Summing up, we arrive at two conclusions. First, support is crucial. We find this as a consistent theme across the interviews, the case studies, and the employer interviews. The type and nature of support both count. However, it needs to be support that is appropriate and that could be 'normally expected'. Special treatment or exceptional benefits could be disarming and disempowering. Second, although not fully discussed above, disclosure is one of the biggest problems faced in the workplace. The difficulty with disclosure is that it can go 'either way'. Furthermore, if disclosure does result in a positive outcome there is no guarantee that this positive outcome will be maintained.

It is disappointing to find that what people with bipolar conditions are asking for in terms of support to gain and retain remunerated employment is no different from what any reasonable person would ask and require. Disappointing, because this is – when provided - good practice in any case, and does not require extensive and costly changes to be made by employers. Disappointing, too, because if the level of discrimination and stigmatisation levelled at people with a bipolar condition was levelled at, say, someone

with ethnic minority status, or with a physical disability, there are mechanisms to engage with the employer to overcome this and to manage the consequences.

While the consequences of 'anti-support' for 'others' ranges from poor working conditions, frustration, and perhaps the need to change jobs and/or live with some frustration, the consequences for people with a bipolar condition can be devastating not only for them but also for those around them.

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9. Appendix.

Appendix I

MDF the Bipolar Organisation Cymru is a user-led organisation, which states: 'the involvement of mental health service users is at the heart of what we do'.

The organisation 'works to enable all people with Bipolar Disorder in Wales to take control of their lives'.

It 'achieves this by:

- Supporting and developing self-help opportunities for people affected by bipolar disorder.
- Expanding and developing the information services about bipolar disorder.
- Influencing the treatments and services to promote recovery.
- Decreasing discrimination against people affected by bipolar disorder.
- Promoting the social inclusion and rights of people affected by bipolar disorder.
- Being an effective and efficient organisation to ensure members receive a unique, high quality service'.

'We', is states, 'are a user-led organisation, with 525 members and 50 associate members. This membership has grown by 10% over the past year and it is our aim to recruit additional members to reach 1000 membership by 2010'.

The services it provides includes:

' * The setting up, support and development of self help groups throughout Wales. We currently have 23 self help groups.

* We run 4 regional meetings a year to enable members to meet, share experiences and to provide a sounding board for current and future services.

* Providing self help Training courses, to enable members to identify triggers and develop coping strategies.

* Spectrum Training. This is for health professionals and other organisations who deal with the public. It is based around the lived experiences of trained volunteers with bipolar disorder.

This is unique to Wales.

*We produce our own magazine for Welsh members called Pendil. In addition , our members get the UK magazine Pendulum.

*We have an early intervention service at mental health units in Carmarthen, Llanelli , Haverfordwest and Aberystwyth. We are currently seeking funding to expend this service in South Wales.

*We have an annual conference for our members. Last year , it was held in Newport and over 180 members attended'.

About Healthy Minds at Work

Thousands of people in Wales sign on to Incapacity Benefit every year – with many citing anxiety, stress or depression as the main causes. With the right support a large number could stay in work.

Supported by the European Social Fund EQUAL Programme, and administered by the Welsh Assembly Government European Funding Office (WEFO), Healthy Minds at Work offers assistance to individuals and employers. This includes:

- Self-help awareness for employees
- Free baseline training for employers
- Advice on risk assessments for stress at work
- Access to rehabilitation and retention services
- Information on early intervention measures
- Suggestions for health promotion
- Support via a new contact centre
- Action and desk research

One in five people in Wales experiences a mental health condition regardless of age, gender, disability, income, education, religion or belief, sexual orientation or ethnicity.

Healthy Minds at Work will benefit individuals, employers and the economy of Wales.

Improving the health of the people of Wales is critical to the Welsh Assembly's vision of a prosperous nation.

Appendix II

Letter to MDF The Bipolar Organisation Members:

Dear Member

29.05.07.

Bi-Polar – Employment/Unemployment Research Project

Confidential.

We are currently examining the link between bipolar disorder, employment and unemployment.

We are carrying out research which will tell us all a good deal more about the employment experiences and needs of members, and how bipolar can impact on those things.

This letter is to ask you to help us with the study about what helps some people with bipolar disorder to work while others lose their jobs. All information given will be treated, by us, in strictest confidence, and we will ensure that the study does not reveal your identity. For more information see our privacy and confidentiality policy (below).

By talking directly to our members, we will be in a better position to, also, establish what support people find effective, what is 'best practice' among employers, and what forms of support they may need to help those with bipolar to work, if they choose to.

YOUR RESPONSES ARE IMPORTANT AND VALID.

It is important that as many of our members take part as possible so that we can get a very accurate picture of their experiences. There is space at the end of this letter to tell us if you would be willing to be contacted, and to take part.

What does 'taking part' entail? It will involve most of our members in a telephone discussion. In some cases it will involve a face-to-face discussion (which will provide more in-depth case studies of these members experiences). A number of members will then be asked to get involved in a Group Meeting to discuss what has emerged.

If you feel that you could help by talking about your experiences (in strict confidence) could you please let us know by signing 'your interest to participate' below.

This study can help to make our services better we hope you agree, and that you will take part.

Please post back your replies in the stamped addressed envelope.

If you would like further information on the research please contact Project Manager: Paul Starling at the Newport Office.

If you would like information regarding your nearest participating group, please contact either myself (south Wales on 01633 244244) or Gail Silver (north Wales on 07841 994053).

We look forward to hearing from you,

Yours sincerely,

Sue Wigmore,
Group Development Co-ordinator.

Thank you, in advance, for your support

Colin Williams,
Director.

YOUR INTEREST TO PARTICIPATE:

Whatever your status (ie employed, unemployed, sick) your response are important and valid as they will give a true picture on the effect of bipolar on employment.

I am interested in taking part: Name:

(In strictest confidence): Signature:

Contact Address:

Contact 'phone number:

-

PLEASE RETURN THIS SECTION IN THE STAMPED ADDRESSED ENVELOPE.

BY (at the latest) FRIDAY, JUNE 8TH, 2007.

After the Research.

Our research will be published . We will be glad to send you a copy of the report by e-mail..

I would like a copy: YES / NO (Please signify).

Please include your e-mail address here:

Privacy and Confidentiality.

We are committed to ensuring complete confidentiality. To do so, we promise:

We will not tell anyone about your answers.

We will only use your replies for the research project – nothing else.

We will ensure that the study does not reveal your identity.

We will not share or pass on any information about you.

We will not use your name or address for a mailing list nor provide your details to anyone else.

No-one outside the research team will see your reply.

We will keep your answers and any records in a safe place and destroy any personal information once the research is completed.

All computer documents, files and email systems which are used to convey or store information will be protected from improper access by passwords.

We will comply in all respects with the Data Protection Act 1998.

You may withdraw your participation, at any time, by contacting MDF on paul@mdfwales.org.uk

Appendix III

Guidance on Approach For Interviewing - Employee – including those who have been in employment.

Setting the scene, building personal rapport:

Hi, my name's (?) and I work as (....) with the Bi Polar organisation.

I'm ringing about the research we wrote to you about and first of all to thank you for agreeing to take part.

Are you okay to talk now, or would you prefer me to ring back (fix time).

It's all pretty relaxed, and shouldn't take more than about twenty minutes.

I just want to remind us about the reason for the survey and a couple of other things about it.

The purpose of the research is to look at the experience of people with Bipolar Disorder and work. It'll cover things like what helps those with Bipolar stay in work, what makes that difficult, how things could be improved, what employers do, or what they might do to improve things.

There are no right or wrong answers.

The purpose is to allow you to share your experiences of being in work, staying in work, managing work.

Are you okay with what I've said so far?

As we put in the letter to you your views and experiences are important. The research will give really valuable insights in to bipolar and issues around work.

This should help everyone who has bipolar, and help everyone else, who doesn't, to better understand issues around these things.

Is that okay?

I just want to remind you of a couple of other important things that we put in the letter when you said you'd take part.

Everything you say is in complete confidentiality. (Please read again just how committed we are to that and that the data will be kept entirely secure).

Your part in this is voluntary. You can stop the interview at any time.

And that I will record the interview and take notes so that we get a really good and accurate picture of your experiences, views, and so on.

Are you okay with all of that?.

Is there anything you want to ask, or for me to explain, before we start?

Because this is a research project we have to use a sort of 'formula' - of questions, basically,

Are you okay to start the interview process?

Interviwe:

So, just to remind you, I'm going to ask about events or support that made a difference when you were in work and that helped you remain in work.

I'll ask you to describe good examples of something that worked well for you that is ...helpful events and types of support

And about - unhelpful events or things that were not supportive.

One important thing to note is that the focus is on the EVENT that happened and NOT on an individual. Please only tell me about everyday events that "made a difference".

Is that OK?

[1] Perhaps we can start with questions about you:

Are you:

Male/female?

How old are you?

If you're working at present - how long have you been in your present job?

How long have you been working for?

[2] The next questions are about your experience of being in work, and staying in work.

EITHER ----

What work do you do:

Private Sector?

Public sector?

Voluntary sector.

Is this the sort of work you want to do?

Are you settled in your job or would you like to change jobs, be promoted, move to a different company?

Does your employer know you have bipolar disorder.

Or -----

If you're not in work at present, what was the last work you did?

Private Sector?

Public sector?

Voluntary sector.

Was this the sort of work you wanted to do?

Were you settled in that job or would you have liked to have changed jobs, been promoted, move to a different company?

Did your employer (then) know you had bipolar disorder.

[3]

Now, I'd like to explore more specifically what was, and is, helpful and supportive for you in the workplace. You can provide as many examples as you like. Please do one example at a time.

What support did, or do you receive that helped or helps you stay in work?
Who provides, or provided, that support?

Look for detailed responses (ie encourage invwee to be expansive).

Why was this helpful?

Thank you. Do you have another example? (Repeat until person has no more examples).

[4]

What I'd like to do now is to look At those things which are NOT helpful to you when you are in work and trying to stay in work;

Can you give me details of those things which are not helpful when you are in work or trying to stay in work.

Look for detail/ Encourage expansiveness on any/all such examples.

Why is this not helpful?

Thank you. Do you have another example? (Repeat until person has no more examples).

Thanks for being so open on these questions and issues.

[5]

Finally, and this is important, is there any sort of support you don't get but which you think would be helpful?

Look for detail, ask person to expand on what they are saying.

Thank you. Do you have another example?

Repeat until person has no more examples.

We are now coming to the end of the interview:

I want to thank you again on behalf of the Bipolar Organisation (your organisation, obviously), for volunteering to take part in this research.

Do you feel you were able to put forward all the points you wanted to?

Is there anything else you'd like to add?

Are there any questions you would like to ask?

If you feel that any of the things you have talked about have caused you any distress, or you want to talk to a counsellor about that please ring our Helpline Number which is 0845 – 634 – 0080.

If you want to talk, further about the research, please contact the Research Manager: Paul Starling on 01633 – 244244 or via e-mail on paul@mdfwales.org.uk

Again thank you for your help.

[pstarling/wfear 06.06.07].

Guidance Notes – Employer.

Introduce Self:

Hello. My name is [name]. I am doing some research work for MDF. The purpose of the work is to find out what sort of support you provide to help employees stay in work. That is, what sorts of things you think are helpful for people to retain their jobs.

I would like to ask you some questions that reflect on your experience of providing support to employees. It's important for this work that you feel able to explain your experiences and say what you feel is important. Your views and experiences are important and there

are no right or wrong answers. This study is completely voluntary. You do not have to participate. You may stop the interview at any time.

You were selected (how they were selected)

I'll explain the questions shortly, but before I do that I'd like to explain confidentiality. All the data is confidential and will be held in 'anonymity' once it has been received. All data will be kept securely at [MDF] and held in accordance with the Data Protection Act 1998.

Do you have any questions?

I'll explain the interview.

Instructions

In this interview I will be asking you to describe good examples of something that worked well, or didn't work well for [you/ for your employees]. I will ask about these as helpful events and types of support. That is, events or support that worked well, and unhelpful events or things that were not supportive.

Each of your these examples should be a description of an event, or type of support, that:

You observed or experienced;

Was particularly helpful (or unhelpful).

Had a clear-cut consequence.

Sometimes an event, an example of behaviour, may have been helpful in one way but unhelpful in another way. This is not unusual.

One important thing to note is that the focus is on the EVENT that happened and NOT on an individual. Please only tell me about everyday events that "made a difference".

Is that OK?

Before we start I'll sum up.

I want to ask you about events or support that made a difference in relation to managing work and staying in work and helping employees manage work and stay in work. I want to hear about helpful and unhelpful events and/or good support or lack of support.

My first question is about your experience of providing support.

Could you tell me about your experience of [providing support to help people stay in work];

Why did you provide the support

How long has it been provided for

How/why did you decide to provide this support

[This may lead on to question 6 automatically]

Now, I'd like to go to ask specifically about what was, and is, helpful and supportive in the workplace. You can provide as many examples as you like. Please do one example at a time.

What support did/do you provide that helped people/helps people stay work and who provides this support;

Look for detailed responses

Why was this helpful

Thank you. Do you have another example? (Repeat until person has no more examples).

What sort of things are not helpful to you as an employer when you are providing support for people to stay in work;

Look for detail

Why is this not helpful

Thank you. Do you have another example? (Repeat until person has no more examples).

Is there any sort of support you would like to provide but don't/can't provide, but which you think would be helpful?

Look for detail, ask person to expand on what they are saying.

Thank you. Do you have another example? (Repeat until person has no more examples).

Shut Down.

That is the end of the interview. Thank you for taking part. I asked you about events or support that made a difference in relation to managing work and staying in work; and helping employees manage work and stay in work.

Do you feel you were able to put forward all the points you wanted to?

Is there anything further you would like to add or any questions you would like to ask?

*****You may contact [contact name?????] if you have any concerns.

Thank you for your help.

[pstarling/wfear 06.06.07].

APPENDIX IV

Interview Report/Recording Form. (Used for all telephone interview participants).

[1]

* Name? (Held in strict confidence).

* Male? Female? (Circle which).

* Age?:

* Working at present? yes no. (circle).

* How long in present job? (weeks/months/yrs).

* How long working for? (overall).

[2] (Questions about experience of being in work, and staying in work)

EITHER ----

What work do you do:

Private Sector? (What sort of work?)

Public sector? (What sort of work?)

Voluntary sector. (What sort of work?)

Is this the sort of work you want to do?

Are you settled in your job,

Or would you like to change jobs,

be promoted,

move to a different company?

[Encourage interviewee to develop their thoughts/and record detail]

Does your employer know you have bipolar disorder.

[2] Or -----

If you're not in work at present, what was the last work you did?

Private Sector?

Public sector?

Voluntary sector?

Was this the sort of work you wanted to do?

Were you settled in that job or would you have liked to have changed jobs, been promoted, move to a different company?

[Encourage intwwee to develop on these things and record the detail].

Did your employer (then) know you had bipolar disorder.

[3] (Exploring what is/has been helpful/supportive in workplace)

What support did, or do you receive that helped or helps you stay in work?

Who provides, or provided, that support?

Why was this helpful? (Take notes for each example).

Do you have another example?

Look for detailed responses (ie encourage intwwee to be expansive).

Encourage intwwee to provide as many examples as possible.

Encourage intwwee to talk about each example one at a time.

Take detailed notes – for each example.

[4] (Exploring those things that have not been/are not helpful when
intwwee is in work/or trying to stay in work.

Can you give me details of those things which are not helpful

When you are in work or trying to stay in work.

Look for detail/ Encourage expansiveness on any/all such examples.

Why is this/has this not been helpful?
(Encourage and record as much detail as possible)

Thank you. Do you have another example? (Repeat until person has no more examples).

[5] Finally, and this is important, is there any sort of support you don't get but which you think would be helpful? In other words those things you wish – in terms of support - were there/were available/that would help those with Bipolar Disorder in relation to work?

Look for detail, ask person to expand on what they are saying.
Record in detail.

Thank you. Do you have another example?

Repeat until person has no more examples.

[pstarling/wfear 06.06.07].

Appendix V

Interview Response Form (Sent to those participants who said they would prefer to be contacted by mail/e-mail).

Letter Questionnaire .

Tuesday, July 17th, 2007.

BiPolar – Employment/Unemployment Research Project.

Dear

Thanks for volunteering to take part. You are one of seventy members who have volunteered to participate, and that's a brilliant response (around 1 in 5 of our membership).

Because the only contact details we had from you in response was an e-mail address, I have decided to send you (via e-mail) the 'format' which has been used to interview most of the others involved.

(There are others who preferred to be contacted either by e-mail or post – and that's fine).

Once you've completed the questionnaire could you please e-mail it back to me on pstarling@talktalk.net

As we stressed in the Privacy and Confidentiality Statement [sent with the invitation to take part in the research] everything you tell us is in complete confidentiality. Your part in this is voluntary, and should you choose too you can withdraw. Your completed questionnaire will form part of the Research Report which will be completed by the end of September and, (as requested), a copy will then be e-mailed to you, most probably in October or November (once it has gone through the usual processes).

Thanks, again, for taking part.

Warm regards,

Paul Starling: Project Manager.

APPENDIX VI

Outputs	Outcomes
A set of categorised experiences from those with Bipolar Disorder relating to retained competitive employment and the support mechanisms that have helped them in retaining employment	Those with Bipolar Disorder taking part will have had a chance to reflect, explore, and share their positive experiences. This allows for practical learning to take place and lays the foundation for the development and enhancement of interventions that have already been demonstrated as successful, acceptable, and usable.
A set of categorised experiences from employers relating to retaining those with Bipolar Disorder in employment and the support mechanisms that have helped them in retaining those with Bipolar Disorder.	As above, but from an employer perspective. This also allows employers to consider their own experiences, and to demonstrate how they have and are addressing the issues that have arisen, and to reflect on best practice. In the instance that employers who do not knowingly employ those with Bipolar Disorder take part this effect may be enhanced especially as we are focussing on successful retention.
A short-life working group of those with Bipolar Disorder to categorise the Critical Incidents	Once this short-life group has been created it may be continued. It will demonstrate to those with Bipolar Disorder, and others, that such a group can be formed to focus on positive and successful interventions
A short-life working group of employers to categorise the Critical Incidents	As above. There is also the opportunity for this group to be continued. In addition, the group has the potential to further a positive working environment for those with Bipolar Disorder within their own organisations.
A bank of Critical Incidents	This bank of Critical Incidents can be mined over time and the CIs expanded into interventions and used to develop new interventions. In addition, the bank will form an invaluable database for employee advocacy as it will be an evidence base for successful support and intervention in the workplace.
A database of international 'gold standard' studies looking at Bipolar Disorder	There are a number of gold standard studies looking at Bipolar Disorder, but there may also be a lack of

	<p>studies in relation to other forms of mental illness. Similarly, the Bipolar Disorder studies may be less well known and disseminated. If it is not already engaged, the MDF could form a Cochrane group in the UK and begin to contribute to the Cochrane database thereby raising the profile of those with Bipolar Disorder.</p>
<p>A final report on the study</p>	<p>The final report on the study will be made publicly available and will serve as an important awareness raising document.</p>

APPENDIX VII

Initial decision making notes re participating Case Studies.-

Case Study A. 63 year old male. Now a mental health advocate in psychiatric units (paid post). "Visit in-patients to provide information and support, listening to peoples issues about care, treatment and mental health in hospitals". His commitment to this work "has grown out of my own disturbed career. He receives regular supervision from his employer, and a lot of support from his team leader, and his manager. Has developed what he calls an Advanced Work Directive/Statement which he has agreed with his employer which is "a statement on how I behave and what work adjustments need to be made" (to reflect the highs and lows). "I have very sympathetic employers and they will make work adjustments. That is incredibly helpful". "I can talk frankly, it is all out in the open, accepted, it enables me to stay in work through periods of illness. It enables me to stay in work which is very important for self esteem and for financial security.

Case Study B. 45 years old female. Employed full-time in a high profile 'media' type role.. Very accomplished. A very demanding and extended "lengthy and arduous" event was being planned so "I approached them, I felt it better that they knew. It would have been problematic for me. I was allowed to be released ... they were incredibly supportive. My line manager knows. My line manager is as supportive as he could be. He went along with my consultant's recommendations without questioning given his constraints (to the demands made on all involved in the project(s). Some colleagues know, people that I know and trust I have told them. My close friends are very understanding they are aware of what I have gone through and are there for me if it should come up again. It's a support network that makes me feel I am not alone in coping should I become ill for specific episodes in the future

Case Study C. 62 years old male. Is employed by a company, and "could go back to work if I could or wanted to" but at present is on 'permanent health insurance'. Work(s)ed as a specialist diagnostic engineer (at a high level). Supportive employers who have provided the (above) flexible package. Prior to working for private sector employers he worked at management level in the nationalised coal industry. ("first spell of mental illness happened when I started in management"). "They were absolutely fantastic, the NCB were. (Hospitalised three times). "Each time if I had a hospital admission then would put me under an NCB doctor and he would see me regularly and each time they would put me in to a less stressful job". The Area staff department (like personnel) were supportive and the head of the staff department would, when I returned to work, each time they left it with me what I wanted to do.

When I had a spell of mental illness in hospital each time the NCB gradually got me back in to work, eased me back in to it. Each time it gave me my confidence back.

It was feeling that working for a company that cares about you, and that you were not just a number. They had half a million employees yet they treated you as a human being and supported you. I was treated just like someone who had pneumoconiosis not as if it was some sort of bad illness".

Case Study E. 57 year old female. Former civil servant who had been "sectioned a couple of times". Could no longer cope with that sort of work. Has worked for ten years in a local family pub - because of the support of the landlady "she calls them my ups and downs'. I have gone from not being able to do anything at all to running the pub when there's no-one

else there, and training people". "When I first went there my confidence had gone. She [the landlady] could remember me before I was ill. She was interested in me and was determined that I would get back to how I was before I was ill. She was very patient and supportive. Sometimes the clothes I wore made me look a bit mental, she would give me help and advice about my hair and appearance. She really boosted my confidence. She's always had faith in me. They trust me with the pub and the money when they're not there. They've always given me praise and that boosted my morale. I've been good for the job and the job's been good for me. I cope. It pays the rent, gets me out socially, and it's been very therapeutic".

Case Study F. 56 year old female. Formerly held a senior position in education. Now "an advocate for people with mental health issues", going with them to doctors, courts, helps deal with advice on debt and other issues. (I wanted to change things because of my own experience in hospital). Gets a lot of support from the mental health charity she works with. Works voluntarily. Has a pension from the education post (diagnosed at age of 50). Has been asked if she would like to work part-time has chosen not to.

Appendix VIII

Case Studies – Guidance Notes re Employer Interviews.

The purpose of this part of the research – is to find out what sort of support you provide to help [Employee] stay in work. That is, what sorts of things you think are helpful for [Employee] to retain his/her job.

Before we start – explain the approach: I'll be

+ Asking you to describe good examples of something that worked well – Helpful events and types of support. (that worked well)

+ And those things that didn't work well for [you/ for your employees] – Unhelpful events or things that were not supportive.

+++ Each example should be a description of an event, or type of support, that "made a difference".

*** We should focus - on the EVENT that happened and NOT on the individual.

To sum up - I want to ask you about events or support that made a difference in relation to managing work and staying in work// and helping your employee manage work and stay in work.

(1) My first question is about your experience of providing support -

- Could you tell me about your experience of providing support to help [Employee] stay in work
 - Why did you provide the support
 - How long has it been provided for
-

(2) Now, I'd like to specifically about what was, and is, helpful and supportive in the workplace. You can provide as many examples as you like. Please do one example at a time.

* What support did/do you provide that helped [Employee] stay in work and who provides this support [Detailed responses].

* Why was this helpful

* Do you have another example?

* (Repeat until person has no more examples).

(3) * What sort of things are not helpful to you as an employer when you are providing support for people to stay in work; [[Look for detail]].

* Why is this not helpful

* Do you have another example? (Repeat until person has no more examples).

(4)

* Is there any sort of support you would like to provide but don't/can't provide, but which you think would be helpful? [Look for detail, ask person to expand on what they are saying].

* Do you have another example? (Repeat until person has no more examples).