



EMPLOYMENT AND MENTAL HEALTH

THE ISSUES WE FACE WHEN LOOKING FOR EMPLOYMENT

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WHAT IS HUG?

HUG stands for the Highland Users Group, which is a network of people who use mental health services in the Highlands.

At present, HUG has approximately 305 members and 13 branches across the Highlands. HUG has been in existence now for 9 years.

HUG wants people with mental health problems to live without discrimination and to be equal partners in their communities. They should be respected for their diversity and who they are.

We should:

- ◆ Be proud of who we are
- ◆ Be valued
- ◆ Not be feared
- ◆ Live lives free from harassment
- ◆ Live the lives we choose
- ◆ Be accepted by friends and loved ones
- ◆ Not be ashamed of what we have experienced

We hope to achieve this by:

- ◆ Speaking out about the services we need and the lives we want to lead.
- ◆ Educating the public, professionals and young people about our lives and experiences.

Between them, members of HUG have experience of nearly all the mental health services in the Highlands.

HUG's aims are as follows:

- ◆ To be the voice of people in Highland who have experienced mental health problems.

- ◆ To promote the interests of people in Highland who use or have used mental health services.
- ◆ To eliminate stigma and discrimination against people with mental health problems.
- ◆ To promote equality of opportunity for people with mental health problems irrespective of creed, sexuality, gender race or disability.
- ◆ To improve understanding about the lives of people with a mental health problem.
- ◆ To participate in the planning development and management of services for users at a local highland and national level.
- ◆ To identify gaps in services and to campaign to have them filled.
- ◆ To find ways of improving the lives, services and treatments of people with mental health problems.
- ◆ To share information and news on mental health issues among mental health service user group and interested parties.
- ◆ To increase knowledge about resources treatments and rights for users.
- ◆ To promote cooperation between agencies concerned with mental health.

INTRODUCTION

HUG is a network of over 300 people with mental health problems and yet when we look to see how many of our members are employed, we rarely get into double figures.

This is reflected in national statistics which show that about 85% of people with severe and enduring mental health problems are unemployed.

For these reasons we thought it would be good to find out from our members the issues they faced regarding employment in the 21st century. (HUG wrote a report on employment almost a decade ago and felt that it was time to update it.) In addition, we are part of the 'Highland Working Group on Mental Health and Employment' and felt that a report such as this could help inform this group.

We held meetings in 11 of our 13 branches and involved 83 people in our discussions.

The series of meetings provided a graphic insight into the difficulties we face in getting work and keeping it. The meetings also revealed some of the anxiety that many of us face when thinking that we may ultimately have to work again when really we worry that it will be too much for us to manage.

These issues are described in this report.

DO PEOPLE WANT TO WORK?

This is a basic, but important question. The majority of us would like to be able to work. For some of us it is our ultimate aim and, unfortunately for us, sometimes a goal that we have little belief we will be able to reach.

The reasons that we want to work are varied but in common with most other people it can provide us with a better income than we receive on benefits.

We want to work for simple reasons:

- *"To be able to say, "I work"*
- *"To be able to respond to the question, "What do you do?"*

However there are many other reasons for working:

It affects how we feel about ourselves. We can feel more self-confident and self-reliant. It can help us with our sense of identity and also help us with feelings of belonging. When we are at work we keep our minds active and have something to focus on and are distracted from having to think about ourselves or our illness all the time. We feel more worthwhile and feel a sense of achievement and purpose in what we do. It shows that we are capable and have something to offer and that the assumption that people with mental health problems can't work is wrong.

It also gives a structure to the day and the week; the days don't stretch out interminably. We have a reason to get up in the morning and we actually end up looking forward to a Friday evening rather than dreading it.

It gives us a chance to get out and meet other people and to build up friendships and networks which all help us to feel that we are a part of our community and society rather than living on the edge of it. The fact that we are earning a wage is great and makes us feel that we deserve the money we get rather than sometimes feeling guilty for being on benefits. It can help us feel accepted by our communities. We can feel that we are doing things together rather than being alone. At last we can feel 'normal' again instead of different.

It can also provide us with something to say in reply when people ask us what we do. If we have to answer this question when on benefits we can feel very awkward and even ashamed.

It can also be a safer environment to be in. When alone in our homes we can be prey to sad thoughts but at work we do not dwell on them so much. Being in work changes our status, provides the possibility of a social life and gives us something to talk about.

It is all about recovery and the idea that with a positive approach to our lives then we have something to aim for and look forward to. The very fact that we are working can keep us well and help prevent relapse. The fact that we have a job can mean that we are 'better' and have reached a new stage of our lives.

WHY DON'T WE WORK OR WANT TO WORK?

Despite the fact that most of us would like to work, many of us feel that we can't work or that it is a long, long way off for us.

The reasons we gave for this were:

The jobs just aren't available and if we are known to have been ill, are even harder to get. This may be even more so in rural areas where work is sparse and seasonal. The jobs available to us may also be the ones which are badly paid with little opportunities to move on. This can make them unattractive.

For some of us, our illness is our greatest barrier; it can make it impossible for us to contemplate work at all. Equally, our medication can be a problem; the simple fact that it can make us drowsy, especially in the mornings, can stop us from being able to get to work.

There is sometimes little incentive to work, and in fact the benefits trap may make work highly unattractive.

The idea of work can be scary in itself and make us worry about whether we would be able to cope. For some of us work is far too pressured an environment to be able to cope with. It has standards that we may struggle to conform to, and this may put us off the prospect. We also worry that if we struggle then we will be letting everyone else down too. What if we have a bad day? Would this be accepted?

We can also worry about the attitudes of others and worry about facing stigma or discrimination from our fellow workers both in getting work and in staying in work. We sometimes create our own stigma by just assuming we will be discriminated against without really knowing whether this will be the case.

We may be unable to work because our illness has prevented us from getting the qualifications and training that are needed.

We sometimes worry that the work place is in itself mentally unhealthy and that the chance of getting help with our mental health when in work may be remote. Some of us feel that we would just be heading straight back to hospital if we tried to cope with a job again. It may just be too

much of a risky step to take. It may be too stressful, pressured and scary and we may not know how to adapt to the culture around the workplace or even just to the general bureaucracy that surrounds work. Sometimes we are so frightened of failure and people's reactions that we don't want to risk experiencing them. We don't want to let ourselves down, or have it made even more apparent how hard we find it to cope.

Some of us also have addictions and lifestyles that are so unpredictable that we would not be able to fit into any conventional job.

Our support and housing can be at risk if we work. We may lose the benefits that pay for our supported accommodation and therefore find ourselves unable to pay the money that would keep our home safe.

For some of us the simple reason that we don't work is because we have become so used to not working, that it no longer features as a possibility. We simply can't work. It is not an option that we can even consider. We may have a reasonable income on benefits, have a lifestyle that is relatively satisfying and therefore feel no need to contemplate work. It would not improve the quality of our lives at all. The feeling of some of us is that, in effect, we are medically retired. We may feel that there is no shame in this and we deserve a reasonable income to support us, which is coupled with no pressure to make us work.

We can find it very hard to cope with other people and therefore work is not an easy option. We can be frightened to reveal that we have an illness to our employers.

The employment history that we have and our sickness record can also make getting back into work unlikely.

We also feel that our lack of motivation can be a hindrance when we contemplate work. For some of us, stability in our lives is vital and employment puts this at risk.

A few of us had a great desire to work but had had very bad experiences with the agencies or schemes that should assist us, such as Disability Employment Advisors or the New Deal for disabled people. This made us very bitter.

HOW ARE WE VIEWED IF WE DON'T WORK?

We agreed that if we work we are accepted by our communities more readily. We also agreed that many people (but not all) were very negative about us if we didn't work.

It reinforced negative concepts around illness and made people think that we are permanently sick.

Some of the views that people hold about us are quite offensive:

"You're seen as lazy good for nothing scroungers"

"They say that you're living off of benefits just for the sake of it."

"They say go and get a job you big lump"

"They think 'dosser'"

"They say what's wrong with you anyway?"

"You're seen as a failure"

"You're seen as a parasite"

" We are seen as second class citizens"

"They assume that we can't contribute."

"People look at us as if we are stupid; as if we are not human and have got horns., We have an illness like any other and should not be segregated."

We felt that unemployment meant that we weren't seen as worthwhile and that we had little status. We felt that people didn't understand why so many of us couldn't work.

Sometimes we were seen as "unfortunate". We were also made aware that other people's taxes paid for our benefits with the implication that we should feel guilty about this. Not working emphasised feelings of being 'different'.

We also felt that other people sometimes had very low expectations of us, and that sometimes they told us that we are not well enough to work and shouldn't consider it. This can be good because it takes a lot of pressure away and yet bad because it narrows our ambitions.

We did agree that some people do abuse the system and that this affects the way others think about us.

We also felt that our reaction to other people's prejudice was important in this. We don't have to let these kinds of comment damage us if we believe in ourselves. However, for some of us, the attitude we encounter from others makes us feel worthless and useless and can make us more ill than we already are. There is a great deal of misunderstanding about us. People didn't understand how we could be experiencing mental illness and on benefits yet still able to get pleasure out of our lives and they found it even more confusing if a few of us could still afford to have expensive things such as a car.

The whole perception of difference can cause us great problems and equally people's ignorance about us can cause them to exaggerate and make up reasons to explain who we are and the situation we are in. Even our families can be ignorant of our condition and judgemental about our situation.

HAVE WE EXPERIENCED DISCRIMINATION?

The vast majority of us assumed that discrimination was widespread. This is due to the attitude that people have towards mental illness as well as ignorance about mental health issues.

Some of it was as a result of the work culture. Everything seems to be geared to profit and even if people agree with the idea of including us in employment the employers will see us as too great a risk to take on.

The main source of grievance was being asked if we had experienced mental health problems on application forms. This stopped us applying for jobs at the very beginning. The Highland Council used to ask this question but we were pleased to hear that this was no longer the case.

Some of us had been advised to be very cautious in what we revealed about our illness when applying for work. Many of us said that we would lie about our illness if applying for work.

We also thought that, although we didn't know of many stories about discrimination, that it would be easy for employers to discriminate, but almost impossible for us to prove that they do.

Some of us have had our history of mental illness shared amongst other employees, which can be hard to cope with and lead to discrimination.

Less clear were the numbers of people who had done job after job but because of illness been unable to keep on working. Was this discrimination or just the reality of illness?

Some of us felt that because of our mental health issues, we had been made redundant or not accepted for interview and some of us experience abuse from fellow employees:

"not another nutter in the workplace."

We can find it very hard to fill in application forms and explain gaps in our employment history and were sure this contributed to the fact that we weren't working. It makes some of us lie which in turn makes work a fragile place to be in especially if we then go off sick.

We had mixed feelings about the areas we lived in. Some of us felt that living in a rural area meant that most people knew us and therefore were less likely to discriminate because they saw the person, not the illness and yet others thought the opposite. People tended to know that we had a mental illness and were therefore more likely to discriminate because of this knowledge. We were aware that practice was variable. Some employers are very positive and keep a job open until we can return to work, whilst others do the opposite.

We felt that people had a stereotype of us as aggressive, unreliable, unable to mix or be part of a team. This vision of us worked against the idea of employing us. However a few of us said that although most of us didn't fit this stereotype that there were some of us who would struggle. Some of us, for various reasons, do have problems with anger and this is hard to incorporate into a healthy workplace.

Some of us had challenged the discrimination that we faced and a few of us were successful in these challenges but most of us hadn't, having little belief that we would be successful. A few of us felt that we might lose our jobs if we reported abuse. Some of us just wanted to hide our problems from everyone else and would never think of challenging injustice.

We did worry that the workplace was sometimes not able to adapt to our needs.

HAVE THERE BEEN IMPROVEMENTS OVER THE LAST FEW YEARS?

Many of us agreed that the attitudes of people were changing and that discrimination was becoming less. Some of us felt that the stigma of mental illness had declined rapidly in recent years. We felt that some conditions such as depression and stress were more readily accepted and people were becoming more open about mental illness and able to acknowledge it and learn from what we go through. We thought that young people in particular were more aware and less scared of mental illness.

In contrast some of us felt that no change had occurred. The same attitudes hold. There is only recognition of the problem, but not a discernable change. The government may promote non-discrimination and people appear to respond, but we felt this was just for appearance.

We praised the work of the Scottish Executive in supporting the See me campaign and felt that the work of HUG had made a difference. We were also aware of initiatives such as the Tribunals for the new Mental Health Act which encouraged people with a mental illness to apply for jobs. Acknowledgement that the experience of mental illness can give a perspective and knowledge that would be of benefit in the workplace was heartening.

Some of us had had good experiences from Job Centres and from Disability Employment Workers. Some of us (but not all) praised Occupational Health and felt that over the last few years they had acknowledged mental illness more and had become more supportive of employees with a mental illness. This is in contrast to what we saw as poor practice in the past. Again a few of us felt that the Highland Council and Health Service had good 'return to work' policies and procedures and also that they were becoming better at helping those of us that could no longer manage at work.

We were more aware of the Disability Discrimination Act and were pleased that it exists. We also were pleased to see more work being done to promote equal opportunities policies and 'positive about disability' practice. This seemed very good. The indications were that awareness was improving but whether that changed practice, we sometimes doubted.

There was a feeling that change had to come through legislation; without this we would be stuck. However, many of us thought that we still had a long way to go and whilst we praised these sorts of initiative, we felt that the message was still not getting through. We had a feeling that bigger employers may be more in tune with these developments and even provide support in the workplace but that smaller employers would still see us as an unacceptable risk. Some of us commented that employers could appear to be positive but when it came to the point of acting on their word, they were less forthcoming. It has proved to be quite hard for people to get placements arranged by agencies such as TAG.

Some of us were very cynical and saw the work place as an environment geared towards making profit and getting as much as possible from employees with little regard to how their health suffered as a result. We felt that employers viewed their workforce as disposable and had little interest in employing anyone with a mental illness.

A few of us felt that there should be quotas set to encourage employers to take us on in work, but others felt that this would signify that we were special cases and this made us uncomfortable. We felt we needed to be employed because of our abilities not because we had a mental illness. We wanted people to realise that anyone can be affected by mental illness and that in some ways it may be good if professionals concerned with our care had also had experience of mental illness and could be open about it. We wanted to emphasise that it can, despite its unpleasantness, enhance some aspects of our lives.

Despite the difficulties that we still faced in getting employment we felt that one of the solutions would be if we could feel more positive about our prospects ourselves and try to be open and honest about our situation and able to believe in ourselves. On a sad note, some of us felt that the reaction of others towards difference was consistently negative and that because of this we would always struggle in work. Some of us have thought of resigning from work because of the difficulties we face. We felt that this was an area where we would need a lot of support in order that the decision we made was one we were comfortable with.

Where there are good examples of employment (because there are some excellent employers) we hoped that their practice could be publicised to encourage others.

WHAT ARE THE MAIN BARRIERS THAT WE FACE?

Some of the barriers we face are:

- We may be too ill.
- Stigma can influence our actions as well as our assumption that we will face stigma. Local knowledge about us can be a barrier.
- We might not have the confidence to work.
- Coming off benefits can be too much of a risk.
- Having other responsibilities, such as children, can also be a problem, as can having other disabilities.
- There may be a lack of understanding. People don't see mental illness or know why we need support or why we struggle in work and therefore they can find it difficult to adapt to our needs.
- The area we live in can be a problem in terms of its opportunities.
- We may only be able to do very poorly paid work.
- Our families may not support us in looking for work.
- Employers and fellow workers may find it hard to accept mental illness and may not be able to cope well with time off.
- Medication can make it hard to work and we may feel like we are failing if we are off sick a lot. We can feel we are letting people down.
- We may find it hard to accept our illness, we may not have worked for a long time and we may put too much pressure on ourselves to go back to work and defeat our aims.
- We can struggle with application forms. It is hard to account for the missing years of our employment history and it can be hard to get references after a long time out of work. Also, we may find the interview too stressful.
- Transport; we can't use it or it doesn't exist and therefore we can't get to work.

HOW CAN WE OVERCOME THESE BARRIERS?

Perhaps we could provide incentives to employers in order that they can see the benefits of employing us but run less risk.

If we could job share flexibly, this might be able to help especially when we get ill.

For some of us work is not realistic but in some situations we could work if the workplace was adapted. If our employers made a genuine effort to create a healthy workplace that reduced the stress we faced at work then it may be much easier for us. Some adaptations are very simple and just involve us all showing humanity, respect and common sense to each other.

It would be useful to get advice about potential jobs and to have assessments or profiling to find out more about our skills, interests and limitations.

Some of the effort needs to come from us. We can learn from our mistakes and experience as well as taking responsibility for our situation. We can find out how to cope when times are rough as well as when things are going well. If we can become positive about ourselves then we stand a better chance. We need to recognise the skills we have, and can gain, and not concentrate so much on our illness and the negatives that surround our lives.

We need to challenge stigma by supporting the work of See me which is very good and is enhanced locally by the work of HUG. Education targeted at employers would be very good but we need to find out what they know already and still need to know. A DVD that they can use could be a good tool as well as more general work in the media to raise the profile of mental illness and mental health issues. The 'soaps' have been good for this in the past. It would be good if employers could be made aware of how many people they have in their workforce who are already ill and that addressing mental health is not just a benefit to those out of work but a benefit to the entire workplace. We should also educate young people as they will be the future employers and workforce.

It could also be useful if staff at job centres could provide more practical help and for them to be provided with mental health awareness

training in order to help them understand our lives and the situations we get into.

We should learn from each other and remember those that never managed to get back into work and gain strength ourselves in this struggle.

WHAT WOULD MAKE IT EASIER TO STAY IN A JOB?

We need to avoid the benefits trap and make people more aware of what already exists. Some of us are especially worried about regaining our benefits if our job doesn't work out. It could be good to be able to work but still remain on benefits, maybe at an enhanced rate; to get some sort of recognition that work is a struggle we want to succeed in, but not at the expense of the security the benefits system represents to some of us. Access to permitted work, where we can earn more but have our benefits protected at first, would also be good.

We need to make the workplace as stress-free as we can whilst recognising that some stress can be healthy. This might be helped by providing counsellors in the workplace and the community, by making our employers realise that anyone can be affected by mental ill health in some way. Perhaps there could be a designated member of staff charged with mental health in the workplace or maybe a mentoring system where a person with a knowledge of mental health is available for discussion and support.

If we are given respect and our contribution is valued and encouraged and we are not overloaded, then we will be less stressed at work and much more likely to be able to work. Being treated with humanity and respect, being seen as an equal and being treated as everyone else would want to be treated makes a huge difference. This doesn't necessarily mean being the same as everyone else; some of us would struggle to conform but we can still make a valued contribution.

Equally we may have regular and sometimes frequent medical appointments; it would be good to know that we will get time off for these.

Some of us have difficulty in getting up in the mornings. A flexible approach to working times could help here. In fact flexibility in general would be very good, maybe even to the extent of being paid to do the work but not having to be specific about when we do it. Maybe we could learn from clubhouses and find jobs that an organisation can commit itself to doing and then share the job between people who are capable of doing it, so that on bad days we can provide replacement workers.

A sensitive approach from our employers could help. This is often apparent when it is clear that they have personal knowledge of mental illness. It would be even better if they made it clear that they have a positive attitude to mental illness and that they don't discriminate and if they made it clear to everyone what they considered discrimination to be. It might also be good to ask our leading employers such as the Health Services and Highland Council to create positive steps to good employment and mental health practice.

Employers could also help by making sure that they are aware of our circumstances and keep our post available if we go off sick for a time. When we are off work and struggling, support can be critical either from within work or from agencies such as TAG (Training and Guidance Unit).

We can also help the situation by being open about our illness and by being confident in our own belief that illness doesn't diminish us. (Some of us don't believe this and feel that it is necessary to hide our illness if we are to stand any chance of getting work.)

Fellow employees can be very important; if we have good relations with our colleagues this can be very helpful and can build up our confidence. Our employers could make work easier by making sure that we all have good working conditions giving us flexibility and time off for appointments as well as making sure that when we do good work that this is praised.

Some of us have missed out on training whilst ill and need a chance to regain skills in order that we can get back into work. Before we even look for employment we often need training and work to build up our confidence. We can also need assistance with application forms and help with our CVs as well as help to get qualifications. We may also need assistance to help us decide how to reveal (if we want to) that we have a mental health problem.

For some of us, help in the early stages by community occupational therapists can put us back onto the path to work.

Overall there was a call to make sure that the labour market adapted to our needs if we are to try to work.

VOLUNTARY WORK

We feel that doing voluntary work is very important for some of us. It is less pressured than mainstream work and yet is a very good way of giving back to the communities that we are a part of and of giving us occupation, contacts, camaraderie, a feeling of achievement and a reason to get out of the house.

Some of us felt that it provides an important stepping stone back into the labour market. It provides contacts, and helps with skills, CVs and references. Others had the idea that it provided a long term occupation in itself. We felt that it might be a very good way of justifying the benefits we get and that maybe if we could commit to this sort of work long term, there might be some room to give us protected benefits to allow us to keep doing this sort of work without taking on the risks attached to mainstream work. Maybe there could be a shift in attitude where some voluntary work is paid a wage in recognition of its importance but the good practice we feel we experience in such situations is maintained without any increase in the pressure and expectations that can be so damaging to us.

"It can be as beneficial as mainstream work, you don't have the same pressure but build up the skills and self esteem and feel that you are doing something for other's benefit. It makes you feel that you are earning the benefits you get."

However a few of us felt that voluntary work had less status and was not always that fulfilling.

THE BENEFITS TRAP

For many of us the thought of coming off benefits seems too much to risk and although we want to work:

"We want to blend into the scenery, to have an ordinary life and start afresh- we need meaningful jobs."

We also wanted to be sure that trying to work was not seen as a sign of being well again. Mental illness is more subtle than this and we may still be very vulnerable even if we try to work or try out things like "permitted work".

We felt that job security was often low and that many of the occupations available to us were low paid. We wanted to be completely sure that there was some form of safety net and that we could return to our original benefits quickly if we didn't manage to continue with the job. We wanted to feel that our benefits were safe and not at any risk if we showed an inclination to try to look for work again.

We also needed to see a good financial reward for going back to work which some of us doubted we would get if we came off of the raft of benefits that we are on.

We also mentioned the stress of attending tribunals for benefits and making applications for benefits. The stress of both of these was so much that some of us became very distressed even to the point that we felt our health was affected. We felt that staff attitudes and understanding were sometimes very poor.

We felt that there should be better links with the Benefits Agency and Job Centre Plus and an acknowledgment that despite wanting to move on, losing our benefits as a consequence was not an option we wanted to risk.

A lot of us are very worried about rumours that it will soon be much harder to get incapacity benefit. We worried that people didn't understand the reality of our illnesses, how hard it was for us to work and the improvement good benefits made to our lives.

Some of us were in the situation where if any member of the family started to work, then the overall income of the family would suffer. This prevented some people from looking for work.

Some of us (through permitted work) have opted to go for low paid but relatively stress free work. The benefits of being in a viable workplace outweighed the disadvantages of a low wage.

There was an opinion that some of the major benefits such as Disability Living Allowance, (DLA) provided such a good income that people felt very comfortable with their lives, so much so that the thought of considering making changes or looking for work was not attractive. We felt this could be a negative step; it allowed people to become resigned to their circumstances almost to the extent that they gave up playing any active part in life itself. Others felt the opposite; we felt that those of us that receive DLA do so for a reason and this is because we have a major disability, to receive a benefit for such a problem is only reasonable and the feeling that we are doing something wrong because we receive benefits is not acceptable.

WHAT SORT OF WORK DO WE WANT?

For those of us for whom work is an option, we want a whole range of job opportunities to be available to us. Everything from social firms and clubhouses (which some of us saw as stepping stones to 'real' employment), to permitted work and therapeutic work or supported employment, to the sort of mainstream work that most people in society aspire to.

For some of us voluntary work is the preferred option. For others part-time work would be ideal, however, for most of us it is unlikely to pay enough to justify the risk.

We also felt that mainstream work is not an option for some of us. Access to sheltered work that was useful and had value could be a very important step for some of us who are more vulnerable and at a point in our lives where this is the most pressure that we could cope with.

Some of us felt that self-employment could be a good option as we may have room to do the work according to our own terms and could adapt our employment to our varying health, but some of us felt that this would end up being too stressful.

A few of us felt that user-run services may be a good way of creating employment opportunities.

We wanted to be sure that any work we got was meaningful and not work just for the sake of saying we were working.

TAG (THE TRAINING AND GUIDANCE UNIT)

This is the main agency in the Highlands that helps people with mental health problems regain the skills and confidence to be able to return to work.

We find this agency very helpful:

"It's very useful;, it's excellent."

"TAG can do it; they are patient and flexible."

"The support is great and when you get stuck you can refer back to the TAG worker."

We welcomed the lack of pressure and the opportunity to learn and to be free to make mistakes. The unit was helpful in getting us work placements and good for references. The unit helped us build up our confidence, gave us new skills and helped us achieve things. As well as creating good opportunities to meet other people, generally we felt that TAG contributes a lot to making our life better and that without it life could be quite hard.

We felt that it was accessible to many of us who would not ordinarily have the confidence or motivation to try to get back to work through a mainstream agency that was geared to the needs of 'normal' people. The workers can be very good and respond to our needs as they arise.

However, there was some criticism that people had to move on at the end of their time there. Some of us found the environment therapeutic and welcoming and didn't want to leave. We also felt that despite gaining confidence and new skills, that all too often when the time came to look for work, the jobs were just not available. We were aware that people turning 65 had to leave the unit and this was not appreciated as they had built up valuable networks that were then lost. We did want to make the point that for some of us there needed to be a balance around being in control of our own decisions rather than being led by some of the workers there. In many areas there is an emphasis on learning computing skills, and whilst this can be very valuable, there is also a need to broaden the range of skills that people can learn at TAG.

A few of us had had assistance from the 'Shirlie' project and from 'Lead' and had found both helpful.

SHOULD AGENCIES SUCH AS TAG BE SPECIALIST OR NOT?

Most of us felt that training and employment agencies such as TAG need to concentrate on people with a mental illness but that there also needed to be agencies that help anyone whatever their background. We have particular needs and experiences that require specialist knowledge and we also feel more comfortable being around people with similar backgrounds. Knowing that we are all in the same 'boat' together takes away a lot of the pressure. Different groups also have different cultures with a range of differing expectations, abilities and attitudes that do not always fit well together.

However, some of us disagreed with this and felt such agencies should deal with people with any disability and also with people with drug and alcohol problems. In an ideal world there would be few barriers and this should be the aim, and then there would be no reason for the specialist agencies that we need nowadays. Some of us didn't go this far, feeling that not all groups find it easy to mix together.

ARE THERE ANY RISKS INVOLVED IN EMPLOYING US?

We had mixed views about this.

Some of us do have difficulty in sticking to conventional timetables and are off sick more than is usual. In addition, a small number of us do have behaviour that can be quite bizarre and which would be difficult for mainstream employers to cope with.

Much as it is hard for us to admit, in small companies that are reliant on a few employees, the frequent absence of an employee can put the business and fellow employees under a great deal of strain. We do feel that sometimes employers are exposed to a greater risks when considering employing us.

However many of these problems would be greatly reduced if we were able to be open with our employer so that we all knew what to expect and what to do if things went wrong.

If we are using machinery then there may be some problems for some of us around the medication that we take.

If we were sure that employers were aware of what a mental illness is like, then this could prevent some of the problems we might encounter.

Some of us felt that we needed to take individual responsibility for our actions. We felt that if we were responsible about our own health, for instance by taking our medication, some of the problems that we face could be avoided. We also felt that we could sometimes benefit from more support when we are at work.

Some of us felt strongly that there were no risks, that we are the same as anyone else, and that any problems were most likely to be caused by poor attitudes to mental health in the workplace or because of a lack of adaptation to our needs at work. We feel that the workplace should be adapted not only to the needs of people with mental health problems but to a wide variety of circumstances faced by different people.

SHOULD WE BE WORKING?

Again we had mixed views on this. Many of us could really benefit from work and think that we should be encouraged to try to get back into it, but others see its benefits as over-rated.

Some of us have just run out of steam and whilst we may feel that there is a pressure to work would probably benefit more if we were helped to accept the fact that we are unlikely to work and that we need to adjust to this new reality without feeling any guilt. We felt that work would create pressures that we couldn't cope with.

Most of us felt strongly that some of us cannot work and shouldn't be made to feel guilty about it.

Some of us also felt that if we were unemployed then we might benefit from activities that helped combat isolation, loneliness and guilt.

CONCLUSION

Current thinking promotes the benefits that people with disabilities, including mental illness, can gain from being in work but the reality of our situation shows that this is a complex area.

Most of us would like to work and to have a wage rather than receive benefits but, for many reasons, not all of us can work. This is not just because the workplace is inaccessible to us, although that is a major reason. It is also because we suffer from conditions that make it extremely hard to work in the way that is expected of most people.

In order for employment to become realistic, we need to be sure that our employers are aware of the need to provide a mentally healthy work environment that benefits everyone not just those with a mental illness.

The changes that would create some sort of reasonable adjustment to our condition are often very simple and include an overt commitment not to discriminate but also to provide an environment that in its culture is humane, positive and rewarding, a place that values us and respects us. These are simple actions and measures that could make work a real possibility for many of us, and yet at the same time many of us are very sceptical that they will ever occur.

By promoting the benefits of employing us and by assisting our employers to act positively towards us we may make employment more realistic. However, at the same time, we need to be sure that the agencies that support us in this quest have the resources to do so effectively.

Some of us would prefer not to work. Our illness is too great to cope with mainstream work and we would prefer to contribute in some other way without feeling any shame in this. There may be alternatives that suit us better, such as voluntary work or we may wish to adjust to the painful reality that we may never work. This is the situation for many of us. We need to know that that if we cannot work, then we need feel no shame for this and should not be penalised because of it.

APPENDIX X

SOME OF THE POSITIVE EXPERIENCES THAT WE HAVE HAD

In this appendix we describe some of the positive experiences that we have had in the world of employment.

1.

In January 2004, I approached a member of staff at Cairdeas Cottage in relation to my having gained a degree of mental well-being enough to want to contribute something back to society. I was sign-posted to HUG as a way of getting involved.

I have been a member of HUG since last January, and have found that it was a real turning point for me on my road to recovery. I get so much out of being a volunteer with HUG, and have become involved in activities such as Awareness Training, making DVDs, and am now on an official work placement with HUG through TAG. I am involved in the compilation of the quarterly Newsletter, which gives me an opportunity to put into practice the computing I have learned at TAG. Most of all, my involvement with HUG has helped me meet people and make some very special friends.

2.

Participating in TAG has been a very positive experience for me. Firstly, I have learned so much more about computing, which has boosted my confidence. Secondly, it gave me a structure to my week, which I really needed as I had far too much time on my hands at one point. Thirdly, it has widened my social circle. I get on very well with the other trainees, and also the staff. TAG has helped me gain enough confidence and sense of well-being whereby I felt able to commence on a voluntary work placement with HUG.

3.

I have had difficulties with my mental health for almost 35 years. In that time I have experienced many episodes of unemployment due to poor mental health. I would return to work after such an episode and try to carry on as before but all too often after 18 months to 2 years I would find it increasingly difficult to carry on in employment and would find myself unemployed once more. Such a situation always lead to poverty

and stigma whilst on benefits and coupled with poor to non-existent clinical services, unemployment never helped towards recovery in any way. It only ever exacerbated the problem.

In 1998, whilst at Ross House, I heard about the TAG Unit from someone who had just left there and had found the experience very helpful, consequently I was referred to the Unit and started in December 1998.

At TAG, as in the work place, timetables had to be followed and workloads met. Unlike in the work place though, those timetables and workloads were structured by me, in cooperation with the Guidance Coordinator, to meet my personal circumstances.

The important feature of TAG was that it was fundamentally my choice as to how much work I took on. TAG provided a safe and empathetic environment for me to experiment with different volumes or intensity of work and to discover what was suitable for me and the difficulties I experience. I could do this without pressure or fear of further damaging my health, risking unemployment or having to withdraw from the Unit.

The Training programme provided the ideal opportunity to mix with others, thus improving my social and communication skills. Here also I could benefit from the knowledge and understanding of those whose lives were not dissimilar to my own. This was better than anything else for assisting me in discovering that I was not alone with my poor mental health and that there were many ways of managing my life. This experience stood me well for when I moved into the more isolated and independent world of employment.

Whilst at TAG I progressed through their Training, Work Experience, and Supported Employment programmes. The experience I gained in managing my mental health and medication whilst at TAG proved to be invaluable. In 2000 I gained employment that met my medical requirements and physical and mental abilities. It is now 2005, and it would be a lie to say that everything has been easy, indeed far from it, but I have now been in employment for an uninterrupted period far longer than I have ever known before. On past experience this would not have been possible without the input from both staff and clients of the TAG Unit.

4.

I was employed in the NHS for thirteen years. During that time I developed the symptoms of a bipolar disorder, resulting in many long periods of absence from my job. My manager was aware of the nature of my condition and was generally supportive. I was often eased back into my role when returning from a period of illness. This might mean stepping up my hours gradually over a few weeks. Eventually I felt I could no longer continue this 'yo-yo' existence, and looked into redeployment. However, this was not possible, so I requested retirement on medical grounds. The Occupational Health doctor was supportive, and my manager very co-operative. The only panic I had was that my pension could not be guaranteed until after the point of no return. In the event, everything was fine.

I have to say that during my time in the NHS I never experienced any prejudice or felt any stigma as a consequence of my mental ill health. During my last month of employment I even organised a presentation, open to all staff, on my experience of bipolar disorder. The session was very rewarding for me personally and produced a lively discussion.

Since leaving full time employment I have had a couple of part time jobs with mixed success since neither employer was very supportive in terms of my health. In contrast, for nearly two years I have worked in a voluntary capacity in a local charity shop where I sort and price music items - records, CDs, audio and video tapes etc. I work for two half days a week, and receive good support from the shop manager. As a result I have missed very few days and am generally able to meet my commitments. The fact that my hours are not rigidly set gives me a flexibility I did not experience in part time employment.

5.

Before I was in paid employment I could control what I did and didn't do completely. I could do whatever voluntary work I thought was important or rewarding. I could control how much I did, and get a work/life balance that was right for me.

I find being in paid employment more stressful than voluntary work although it can be very rewarding when it is going well. For me however, the stress of employment is less than the stress of dealing with the benefits system.

One of the challenges of returning to paid employment for me was that because I need more leisure time than most people, I can't work full-time. The job has to be better paid than a full-time job would be, in order to have enough money to live on and so it needs to be quite a skilled job where more is expected and the pressure is greater.

6.

I have a diagnosis of schizophrenia but generally keep very well. Certainly well enough to work.

I have been in my present job for nearly 10 years and love it. It gives me so much; not only a good wage but the opportunity to do things that I enjoy and believe in. I meet incredible people all the time. I work with fantastic fellow employees. I have variety, responsibility and control over what I do. People are great at praising me when things go well and at supporting me when I have minor crises of confidence.

The job is a central part of my life and helps me define who I am and how I see myself. It stops me feeling miserable about myself and gives me something to do and to look forward to. It gives me things to talk about and distracts me from sad thoughts. It is constantly changing and consistently rewarding. Without it I don't know what I would do. I would probably curl up in a ball in a corner and give in.

There has been no problem with the fact that I have a mental illness. Everyone is aware of it. It is inconsequential, just a part of who I am that is acknowledged, but needs no further comment. I don't know if it would have been different if I had needed lots of appointments or time off. I hope not. I feel completely accepted here as a person with talents and quirks that we all adapt to and am so glad that I don't have to hide or feel ashamed of my illness. That makes such a difference.

7.

I'm Pauline, and in 1999 I became ill again with anxiety and depression. I was on six and a half pills a day. In February 2004 I got a part-time job as a telephone canvasser introducing people to the idea of buying a new kitchen over the phone. In the previous November, I had had a relapse, so when I first started telephone canvassing, 12 hours a week was all I could manage. What it did was add a structure to my day.

It is a job that requires verbal skills and I have enjoyed this. Perhaps because when I was tested for Dyspraxia, my verbal skills were found out to be good. At work I found I was not alone, and that there were other people who had similar mental health problems.

When not involved in the sale of kitchens, I am doing a vast amount of voluntary work with HUG, at an old peoples day centre and gardening on a small holding. Now I feel ready to come off Incapacity Benefit.

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With thanks to all the members of HUG, and other mental health service users, who contributed to this report.

(Please feel free to photocopy this report)

However if you use this report or quote from it or use to inform your practice or planning please tell us about this first. This helps us know what is being done on our behalf and helps us inform our members of the effect their voice is having.

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