



# BENEFITS "LIVING OR EXISTING?"

*A REPORT ON THE BENEFITS SYSTEM  
AND PEOPLE WITH A MENTAL ILLNESS*

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## HIGHLAND USERS GROUP

The Highland Users Group (HUG) was established on 11 June 1996.

Its aims are to:

1. Represent the interests of users of mental health services living in the Highlands.
2. To identify gaps in services and to find ways of improving services for mental health service users.
3. To provide information about mental health issues to users living in the Highlands.
4. To participate in the planning and management of services for mental health service users.
5. To pass on information and news amongst mental health user groups in the Highlands and to interested parties.
6. To increase knowledge about resources, alternative treatments and rights for users of mental health services.
7. To promote co-operation between agencies concerned with mental health.
8. To promote equality of opportunity and to break down discrimination against people with a mental health problem.

At present (December 2000) HUG has 219 members and 13 branches in:

- ◆ Caithness
- ◆ Sutherland
- ◆ Easter Ross
- ◆ Wester Ross
- ◆ Nairn
- ◆ Inverness
- ◆ New Craigs Hospital
- ◆ Lochaber
- ◆ Skye and Lochalsh

Between them, HUG members have experience of nearly all the mental health services in the Highlands including Child and Adolescent Services and Services for Older People. However, our reports mainly reflect the views of 'adults' with experience of mental illness.

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# INTRODUCTION

## **WHY LOOK AT BENEFITS AND MENTAL HEALTH?**

This Report was inspired by the fact that the majority of the members of HUG are in receipt of benefits. Many members have been on benefits for a number of years and some expect to remain on benefits for the rest of their lives.

HUG members have often commented on the complexities of having to deal with a large bureaucracy such as the Benefits Agency, on how hard it is to live on a low income and how intrusive and personal it can feel when making a claim for benefits.

This Report attempts to show what it is like to live on benefits and how life could be improved for people who have to deal with the "system"

The subject was discussed in the different HUG branches that exist across the Highlands – The discussion occurred in an informal way based around a series of questions such as:

- ❖ What values should influence the various agencies?
- ❖ What is it like to be in receipt of benefits?

However, as in all HUG meetings, topics changed and opinions grew as the series of meetings progressed.

In total 60 members of HUG participated in group discussions on the subject and a number of members contributed to the subject individually after the discussions had taken place. The Report itself was sent out in draft form to the 23 members of the HUG Round Table to check both that it reflected HUG views and was still accurate. It was also sent to the Inverness CAB Advocacy Project as a further check on its technical accuracy.

There are many quotes in this report. These are taken from users of mental health services during HUG meetings.

Technicalities to do with particular benefits were raised at all the meetings – these have rarely been recorded both because the benefits system changes frequently thus making any record out of date quickly and because we believe the various welfare rights agencies are better at dealing with these subjects rather than HUG which has an expertise in painting a broad picture.

A previous Report "Employment - A Report on the views of Highland Users Group on Employment for people with mental health problems and ways in which access to employment can be made easier" may be read in conjunction with this Report. The issue of benefits is raised in a number of other HUG Reports. Reports that HUG has produced on "Quality" and on "Ward Rounds" may also be of use when looking at the recommendations we make. For a list of Reports please contact the Highland Community Care Forum Office on 01463 718817 or write to them at the address on the front cover.

The subject of Welfare Rights in the Highlands is also covered in the Report "Mental Health Advocacy Report 1999 - 2000" of the Inverness Citizens Advice Bureau Advocacy Project available from 103 Academy Street, Inverness IV1 1LX.

## **WHY SHOULD WE HAVE A WELFARE SYSTEM?**

In recent years the concept of the welfare system as a whole in the UK has come under question. Members of HUG have very strong feelings on this subject, some of the views expressed were as follows:

- "The benefits system is a vital component of our society, which acts as a safety net for people who would have considerable difficulty in coping otherwise"
- "If you are mentally ill, and because of that cannot work, then the welfare system should ensure that you do not suffer as a consequence. You shouldn't lose your house, have problems with paying your rent or have problems in obtaining necessities such as food and heat."
- "We feel entitled to it. We have paid our taxes in the belief that society, of which we are a part, will take care of those people who, for whatever reason, find themselves unable to work."
- "If people saw benefits for what they are, a government run insurance scheme, then there would be no stigma. The stigma is a result of propaganda from the state stating that people should not claim from a scheme to which everyone has paid in."
- "Benefits are not a charity and should not be thought of as such."

## **RECOMMENDATION:**

The current welfare system remains a vital way to provide for people who cannot work, including those who may be disabled by mental illness. It should remain so.

## **WHAT VALUES SHOULD AGENCIES ADMINISTERING BENEFITS ADHERE TO?**

The values of the Benefits Agency can give powerful signals about the views they hold about their clients and the philosophies that they adhere to.

HUG members considered the values and principles that they would like the agencies who administer their benefits to hold. These are listed below:

- ❖ It should be simple.
- ❖ Easy to access.
- ❖ Not stressful.
- ❖ Come out to you if necessary.
- ❖ Provide continuity.
- ❖ Be a one-stop shop.
- ❖ Employees should have Mental Health Awareness Training (*and recognise the needs of other vulnerable groups*).
- ❖ It should recognise that unclaimed benefit is an indictment of the system.
- ❖ They should tell you what you are entitled to.
- ❖ Benefits should be seen as assistance - not hand outs
- ❖ Claimants should be treated as individuals: they should be given opportunities and they should be given security.
- ❖ There should be no denigratory labels or attitudes attached to people claiming benefits.

## **RECOMMENDATION:**

Employees of the benefits system and people determining the direction of the benefits agencies should listen to the views of their clients and make the values by which they operate clear to all.

# WHY DO PEOPLE WITH A MENTAL ILLNESS END UP ON BENEFITS?

There are a number of reasons that people with a mental illness end up on benefits:

- ❖ The illness itself.
- ❖ Employers do not adapt to the needs of people with a mental illness.
- ❖ Employers discriminate against people with a mental illness.
- ❖ People with a mental illness have become unemployable.
- ❖ The social effects of mental illness.
- ❖ The benefits system itself.
- ❖ A collection of difficulties building up together.

## 1. Mental illness can stop people working:

- “We have a lack of confidence, low self esteem, we cannot concentrate, we may be agoraphobic....”

People may have other problems such as not being able to get up in the morning or being so ill that they cannot respond to the normal demands of the workplace.

## 2. Employers have not adapted to the needs of people with a mental illness:

- “We need flexible employment opportunities in order to work, with possibilities for time out, different work times or extended periods of sick leave. At present this is not possible.”

Many people feel that if only the demands of the workplace could reflect an awareness of the differing needs of people with a mental illness then employment would become more likely and the benefits system used less.

The Disability Discrimination Act covers people with a mental illness and needs to be adhered to when looking at employment for people with a mental illness.

## 3. Employers discriminate against people with a mental illness:

If a person has a mental illness then employers may be reluctant to give them employment. This may be evident in questions on application forms asking about a

persons psychiatric history or in the reluctance to employ people through unnecessary fears of violence, excessive sick leave or dependence on other people.

Equally people may be discouraged by their own attitudes - they may feel that it is a waste of time applying for work, perhaps because they don't believe in themselves or because they think that they would inevitably lose their job in the future because of the recurrence of illness.

#### **4. People may have become unemployable:**

People may have been out of work for so long or continuously ill for so long that the prospect of employment in the near future stops becoming a sensible option.

#### **5. The social consequences of illness:**

Some people with a mental illness may have difficulty in keeping relationships or in keeping their tenancies.

This may result in people having to move area frequently or becoming single parents - both of these situations may make it harder to find work.

#### **6. The Benefits System itself:**

People with long term illnesses may stop having something to look forward to, they may no longer feel a pride in being a part of society or even that they are part of society.

This may make ways out of the system hard to achieve.

Some people may develop illnesses because they are living in harsh impoverished conditions - the mental illness they develop may prevent any escape thus creating an unbreakable cycle.

#### **7. A collection of difficulties building together:**

People with a mental illness may end up on benefits due to a number of crises that reinforce each other - for instance mental illness may lead to the loss of a job and in turn to the loss of a house and alienation from family and friends .The combination of



these and similar factors may mean that a prolonged time on benefits is inevitable.

**RECOMMENDATION:**

Although illness preventing work is the main reason people need benefits - making employment a viable option through the use of the Disability Discrimination Act and awareness training with employers and helping people to believe in themselves (for instance through schemes such as the Training and Guidance Unit in the Highlands) could reduce the need for some people to remain on benefits.

# GETTING INVOLVED WITH THE SYSTEM

## PEOPLE WHO COULD, BUT DON'T, APPLY FOR BENEFITS

Some people with a mental illness do not apply for benefits at all. There are a number of reasons for this:

1. **STIGMA:** There is a stigma about claiming benefits and also about revealing a history of mental illness.

- Some people will not make claims because they are too embarrassed .
- Other people (*some of whom live on the West Coast*) will not have anything to do with the system and prefer to rely on their own resources and casual work rather than claiming welfare benefits.

2. **CRISIS:** Some people find that they need benefits at times of profound personal crisis:

"When you are claiming you can be in desperate need of support. It can be very hard because claiming benefits and becoming ill can all come at once. Facing the situation can be very traumatic. Your first contact can be at a time when you realise that there are major changes in your life and you may just be realising that you are ill."

This can make it very hard to make a benefit claim a priority.

3. **ILLNESS:** Some people are too ill to claim benefits – when a major achievement for someone with depression may be deciding to go shopping or to have a cup of coffee - filling in a benefits form may be an insurmountable task – forms for benefits often literally end up at the bottom of the pile of letters or under the couch.

### **RECOMMENDATION:**

Many people with a mental illness may need assistance to claim benefits which could include visiting them in their homes and providing more publicity about peoples rights to benefits.

## CLAIMING NEW BENEFITS

Some people may not claim new benefits because:

1. They do not associate benefits like Disability Living Allowance with mental illness:
  - “Many people with a mental illness do not know that Disability Benefits apply to them, especially as the questions are often not relevant - you have to trust the questions and use the right phrases to fit in and get the benefit.”
2. They do not think that they are ill enough or deserve benefits. They may think that they are just going through a short “blip” and there is no point in claiming.
3. They do not want to admit to themselves how bad life is.
4. They are not aware of the range of benefits that they can claim.
5. They may not be aware that they have a mental illness in the first place:
  - “If you were manic you wouldn't even think of applying for benefits. You do not feel pain or problems and often do not acknowledge illness.”

### **RECOMMENDATION:**

People need help with understanding that mental illness can be defined as a disability and again may need outreach and assistance in claiming benefits.

## FILLING IN THE FORMS AND MAKING THE APPLICATION

This is an area where there was the most concern from members of HUG. Making contact with the Benefits Agency and then getting appropriate advice, information, and help seemed to be a major problem.

### **What it feels like making a claim:**

Below are a few of the feelings that HUG members have felt about making a claim :

- “What do you do if you are going in for your first claim? Light a few candles!?! – It is confusing and we should help each other.”
- “If you are mentally ill at the same time that you are claiming it can be horrendous. You can get bogged down in red tape. There is no understanding of the illness – it just escalates your illness and you just give up because it is too much and too stressful”
- “You get confused and muddled until you say F\*\*\*\* it i’m not doing it” – and they say “there’s no need for that kind of language.”

### **RECOMMENDATION:**

Benefits agencies need to make every effort to ensure that the stress of making a claim is minimised. The HUG Reports on “Quality” and “Ward Rounds” may be useful guides.

## **Information and Alienation**

### **Knowing the System:**

- “People often do not hear or know about the benefits that they are entitled to, they are often refused the first time that they apply and it can be a good time to turn to the support of a community psychiatric nurse.”

This comment (about getting outside help) was made again and again in the HUG branches as well as the need for a good understanding of the "system" that they are faced with.

- “There are so many rules and regulations that it alienates you as a person and it is not possible to see the people for the rules.”

### **Simplicity:**

There was a call to make it easy for people to fill the forms in – some forms are so complicated that filling them in on your own is not sensible:

- “Getting into the benefits system can be awful. When you are going in for the first time, no one tells you what is happening, you have to find out for yourself. It is a jungle of forms. It is an awful struggle and as soon as you get to know the rules they change them. It is almost like they do not want you to understand. They keep moving the goalposts”

### **Knowing where to look:**

The problem is not always lack of information - it is knowing what is needed:

- “There are a lot of pamphlets plastered all over the place- you do not like to look – what one do you need?”
- “There is a maze of leaflets on benefits. You almost need help to work out what to read. The information is not volunteered”

### **Knowing when to get help:**

It may also be the case that the time is wrong:

- “The time when people need information is often the time when they are least able to take it in. You do not know how to access the information or how to take it in.”
- “Not knowing what to claim enforces resentment and creates problems. There should be someone to guide you through the system. Someone who will tell you what to do and how to claim and what to do if you do not get what you need. This could be provided by an advice agency with someone to accompany you, support you and give you information. An advocate.”

### **Filling in the form itself:**

The task of actually filling in a form was also seen as very stressful and complicated:

“The forms have traps in them and are frightening. In our situation we need help. It can be hard to read and write due to illness and medication ...”

“ When people are filling in the forms, they may not be able to relate to the questions. They may be difficult to answer and not appear relevant.”

"I couldn't cope with the benefits, just looking at the form, just looking at the words. The medical people helped enormously."

Some people find it hard to write about the severity of their condition when making a claim and may therefore lose out:

"I wrote what I would like to happen to me. I was trying to be positive, so all my benefits were stopped."

**RECOMMENDATION:**

- There should be a clear guide to benefits for people with a mental illness.
- There needs to be some rationalising of the information that is provided.
- Benefits forms should be simple enough for people to fill them in themselves.
- People need access to assistance in understanding and negotiating the benefits system.

# **HOW ARE PEOPLE TREATED BY THE “SYSTEM”?**

## **THE BENEFITS SYSTEM ITSELF**

There was a strong feeling that the benefits system is not geared to the lives of people with a mental illness or even to the lives of most people who claim benefits. It was thought to be particularly unwieldy when dealing with people from rural areas.

## **THE BENEFITS SYSTEM AND PEOPLE WITH A MENTAL ILLNESS**

People with a mental illness often do not seem at first glance to be ill or unable to work. The symptoms of illness are not always present and people may go through times when they are fine and then the next week be too ill to communicate or look after themselves. Many people also have unconventional lifestyles. All of this can make it hard for people to get the benefits that they are entitled to:

- “When people are mentally ill their sleep patterns can be very erratic, and yet they may not be signed off sick by their doctors and so, when people stop signing on for their benefits, they can lose them because their illness has not been recognised.”
- “People have to fit into a category for the computer – so, however nice the person on the phone is, if you are not convenient and easy to categorise (as so many people with a mental health problem are not) it can become very difficult for your claim to be processed.”
- “It is easy to give up because you cannot cope with too much stress and pressure. They look at “Mr Jobless average” and they can cope with that, but I found I was just a number, they did not care about my situation. If they understand they can be quite good but if you do not fit in with the norm then they will not understand and you will get frustrated and give up.”

Many of the HUG members thought that there should be specialist workers within the benefits system who understood the particular condition or disability that people had and who could take them through the system sensitively.

- “People can’t see mental illness, therefore it doesn’t exist. To them this just leads to negative, unjust judgements. There should be staff with a specialism in mental illness.”

### **RECOMMENDATION:**

Mental illness is a disability. In order to deliver an effective non discriminatory service the Benefits Agency needs to look at the needs of people with a mental illness including their social circumstances.

### **Disability Living Allowance (DLA):**

Claiming Disability Living Allowance came in for a lot of criticism, for the complexity of the forms, the medical examination and the frequency with which people with a mental illness were refused DLA. Only to then get it when helped with an appeal:

- “The DLA medical can be awful. You can be asked a lot of silly questions and only allowed to say “yes” or “no” and not to explain.”
- “If you fill in the DLA form yourself you will be refused, as you don’t know how to say what is needed. It is very difficult to know how to put it.”

The process of applying for benefits can also be highly distressing with people being forced to confront painful realities when filling in forms:

- “When you fill in the DLA form and read it over you feel “oh my god, am I really that way? It is a real downer and it really affects you afterwards.”

There was also considerable confusion about how people got certain benefits – members being aware of people in similar situations but on different benefits:

- “It seems to be a bit of a lottery in how you are assessed and how likely you are to get Incapacity Benefits or Disability Living Allowance.”
- “DLA depends so much on other people agreeing about the illness and the need for Benefits .... People need professional help with DLA . This is not automatically given.”



## **RECOMMENDATION:**

- People applying for DLA should automatically be offered help in making the application.
- Services should be sensitive to the affect an application can have on a person's mental health.

## **HOW THE BENEFITS SYSTEM WORKS WITH PEOPLE GENERALLY**

The main feeling about the system itself was to do with the bureaucracy, delays and red tape - all of which put pressure on claimants.

There was also a strong perception that the benefits system was not primarily there to help people maximise their benefits and that in fact success was measured in how many people didn't claim benefits.

Lastly there was a feeling that when mistakes were made that it was not the agency that was held responsible, instead, claimants were made to feel the brunt of any problems to do with benefits:

- "When you are going into the system you get passed from pillar to post, especially when you first claim, you can go from person to person and place to place not knowing what is happening."
- "Strange words and phrases are used and you are not voluntarily given information."
- "It feels as if it is up to the claimant to prove that they need a particular benefit, that they will rarely be told what they could claim and that the benefits system is trying to minimise what it pays out - which gives a very negative message about the people who have to claim benefits"
- "...yet when people are given the wrong sort of benefit the responsibility to realise it and change it rests with them."
- "It can also seem very bureaucratic sometimes when there have been changes in types of benefits that are time consuming but result in little change in income but a lot of work."

- “Are they trying to stop you getting benefits? Is it because they cannot tell you anything? Perhaps there is a problem of public liability if they tell you something wrong about what you are entitled to. Perhaps they are guarding their backs because they are not sure they should be helping you get more money.”
- “Getting a benefit can mean being prepared to wait and be patient. Some people have waited a considerable time to get the benefits they were entitled to.”
- “The Benefits Agency’s role is not to advertise what it can do. In an ideal world we would all get what we are entitled to.”
- “They dehumanise you. You become a part of the system and get lost because they do not look out for you. You become a number in the system, not a person, but a National Insurance number.”

**RECOMMENDATION:**

The Benefits Agency should seek to maximise the claims of clients and should take responsibility for any of its mistakes or delays.

**THE BENEFITS SYSTEM AND RURAL ISSUES**

There was a feeling that cost of living issues and employment patterns in rural areas all conspired to disadvantage people on benefits in rural areas:

- “If people could do seasonal work which is the main form of employment, and not put their benefits at risk then that would also be good but unlikely.”
- “For instance, in a city, access to a phone may not be too important whilst in a rural area it can be vital - but people cannot afford it. The same applies to ownership of cars or in trying to pay deposits for somewhere to live”
- “Work ... is often seasonal and temporary and may last only a few hours or a few days. This does not fit in at all to the benefits system, which will not respond sensibly to this. This work also carries with it almost no rights and is often exploitative. However it is often all there is.”

## **RECOMMENDATION:**

There needs to be a flexible response to casual work and the extra cost of rural living needs to be included in payments.

## **WHAT IS THE ATTITUDE OF STAFF DEALING WITH BENEFITS?**

The whole process of claiming benefits can be greatly improved by the attitude of the staff who are dealing with a person making a claim. It will also be influenced by the views that a claimant brings to the process. HUG members had very mixed views about staff attitudes although there seemed to be consensus that improvements had occurred over the last few years.

There was a strong call that staff underwent mental health awareness training to help them in their work with people with a mental health problem.

### **Good Attitudes:**

There was a feeling that some staff were operating in a limiting environment:

- "The Benefits Agency staff are trying to do their best - they can only do what the law states - some of them must get very frustrated at the things that cannot be done."
- "The staff used to be absolutely awful in their attitudes but have improved dramatically in recent years."
- "They are powerless too. The system is dominant. All we can really do is be nice to each other to make an inflexible system as nice an experience for all of us as possible."
- "The Housing Benefits service is very good, they know about mental illness and will take time to sort out your problems while remaining pleasant."
- "Some people in the DSS are very good at this; they are firmly on your side and will go out of their way for you. There is a feeling that some of them are sticking their necks out to help you, and this is how it should be."

There was a feeling that it was almost impossible for workers to spend time with individuals:

- "The benefits workers are snowed under with work"

But also that not everything should rest on a pleasant manner:

- "Genuine pleasantness also means that there should be commitment. If people are trained to be pleasant then they have to follow this up with actions that reflect the attitude that they are passing on."
- "If they see you are not worked up then they will begin to relax – some people are nice, some reassure you and are not judgmental"

### **The Bad Practice:**

The main points made were to do with the lack of awareness staff had of people with mental illness, their general attitude, and the attitudes people brought themselves:

- "The computers are often the source of blame for anything that goes wrong. Which may be true, but that doesn't help the claimant who is constantly told it and ends up feeling brushed off. It is also very hard to get cross with a computer to any good effect!"
- "They are terribly nice, but essentially if it is too difficult they slide out of it and can't be pinned down and avoid responsibility. You are really given the brush off but because they are so nice you can't complain."
- "Attitudes can be offensive and antagonistic."
- "The benefits system should treat us all like human beings but it doesn't. For example one person went without money for 5 weeks and phoned up to ask what was happening and was told - "You know there are other people in the queue". She then asked how she was meant to feed her child at which point everyone lost their temper."
- "The Benefits Agency does not have a good name, as many people have heard stories about it, people encounter it with fear and apprehension, which leads to a self-fulfilling confrontation."
- "Many people communicate by phone or letter and the incapacity staff are helpful. But when you go in they are not generally nice, perhaps it is their workload,

perhaps they are pushed and pushed to work and they need more staff or the staff are not coping with what they are going through. They can be treated badly and in turn treat us badly. The attitude is often patronising.”

- “... and then they look down their noses at you. We employ them, I wish that civil servants would remember the “civil” and the “servant”.
- “The Benefits Agency can be very intrusive and this can be very hard if you are already paranoid. That is hard enough but when your paranoia becomes justified it gets worse.”
- “Responding to the questions can make you feel stripped naked.”
- “When I was at the tribunal, I felt as though I was on trial. I felt they were trying to prove me a liar and this is hard to take.”

### **RECOMMENDATION:**

Benefits Agency staff should have Mental Health Awareness Training as part of their induction and ongoing training.

### **The Attitudes of the Public:**

Whilst there was a strong feeling that the attitude of the public to people on benefits can still be very negative, it is not all bad and the affect that it has on people can depend on their own attitudes and on the circles in which they mix.

- “People who are poor and need benefits are seen as lazy and helpless and not full citizens. Those who are mentally ill or homeless are third class citizens who are seen, in addition, as being threatening, antisocial and violent.”
- “Some people think that they are better than others, but such attitudes can be turned around. It is easy for people to be judgmental and to look down. We need to help people remove this feeling... We need a shared understanding of people. We can all be patronising in lots of situations and can unwittingly put people down for the best of motives often because we do not understand.”

It can depend on where you live:

“The majority of people here are on benefits. There are so many that there is no

stigma. At one time children who got free meals were picked on in the playground but now it is the other way round."

"To be worthwhile you have to have a job. We do not believe this but society does. Because we have no work we are treated as worthless people. We are not even people. To be a person you have to have a job."

### **RECOMMENDATION:**

The positive contribution of people on benefits and the reasons that people need to be on benefits should be publicised and the media encouraged to be responsible in its reporting.

## **WHAT DO PEOPLE FEEL ABOUT GOING ONTO BENEFITS?**

For many members of HUG this is not an issue - being on benefits is a part of life which may be a constant or a short event in peoples' lives. However for some people it is a big issue as shown below:

- "The move onto benefits can be great shock and the period of adjustment hard to cope with. If you are made redundant then everything changes. You get bored, there is nothing to do, and you run out of things to do, you lose control of your life and you feel like a third class citizen. You want work but cannot get it. Your money is running out and there is nothing to do - a vicious spiral."
- "We can lose confidence and self esteem. Being on benefits can cause illness...."
- "There is, for some people, a lingering guilt that they have to rely on benefits."
- "If we think of ourselves as lesser people because we are on benefits then it can be very hard."
- "Some people will put down those who are on benefits - that is their problem, we won't be put down by them"

## WHAT IS LIFE LIKE ON BENEFITS?

Life on benefits can be hard to cope with but not for everyone – being on the full range of disability benefits can give people an income that they are happy with. Although poverty is an inevitable feature for a lot of people, other factors about being on benefits include responding to change, isolation and having something to do.

### **Monotony, Isolation and Motivation:**

- “There is the demoralisation of having baked beans on toast for the umpteenth day, until you no longer want to eat at all.”
- “There is the demoralisation of living day by day, but without ever having any luxury. You can end up existing rather than living.”
- “Living alone and on benefits can make you extremely isolated. You need to be a certain type of person to survive. It can be very hard to cope to keep motivated and to find a reason for getting out of bed.”

### **Change:**

- “After spending your benefit you can end up with very little to live on. Any expenditure can seem like a crisis.”
- “A big problem is unexpected costs, where people need loans that they need to pay off and can end up in debt. Sometimes it should be acknowledged that some of these payments are for necessities not luxuries.”
- “A change in income can cause huge problems. You make plans and these can be ruined by changes in income and benefits. Being mentally ill can affect the way you cope. Sometimes people will go through a bad spell and stop being able to budget properly, from going on spending sprees to not claiming – to buying things out of budget to relieve the monotony.”

### **RECOMMENDATION:**

- There needs to be access to funds to deal with sudden changes in circumstances.
- People should have help with debit management.

## **Having a little extra:**

People on benefits can earn small amounts per week. This amount will vary depending on which benefits a person is on and their individual circumstances. Members of HUG made the point that in the context of their total earnings this can make a huge difference especially when in the context of also having an occupation.

However there are some people who would say that the payments for training or placements can get close to exploitation.

- "I find life OK but I would be slipping if I did not have a small job – just a small change makes a big difference."
- "Being able to earn the minimum can be great – getting up to the upper limit can transform your life."

## **Poverty:**

- "Money does not necessarily make you happier, but it can make you unhappy. For instance how do you afford any major items? Loans are very hard if you have little income"
- "If you are on a low income it is very likely that you will have a poor diet, poor clothes, poor housing and little social life. Everything is a struggle and is hard - which increases stress and unhappiness."

## **The Good Side:**

Some people felt that being on benefits was not always a negative experience – some people had an acceptable income and others could adapt:

- "It can be good if you can encourage self motivation and self sufficiency. It can be good for some people."
- "It is very important to acknowledge that not all work is paid work and that sometimes it shouldn't be paid. However it does have great value and is carried out all the time by people in receipt of benefits."
- "If you feel that you have enough money coming in and that it is secure, then life can feel a little better."



## LIVING IN A NURSING HOME OR BEING ADMITTED TO HOSPITAL

Considerable concern and anger was expressed about the situation for people who had their benefits reduced to an "allowance" when living in hospital - often after being in hospital for more than four or six weeks (although again this can vary) or in "special accommodation" or when getting respite care for which users have to make a contribution.

It became impossible for people to buy even basic luxuries which people thought had a major impact on their quality of life and prospects of recovery.

- "The elderly and the vulnerable and the mentally ill tend to get treated the same way - badly - especially if you are in a nursing home - not necessarily badly by the staff, but badly because you can't afford to do anything."
- "It can be a terrible struggle to live. You can just sit around all day feeling trapped."
- "How can people expect you to look forward to thinking of getting well when you can't even think of treating yourself to a chip supper?"
- "People who come to a place like this (a nursing home) need a prospect of hope and enjoyment. People are young here, they should have a life to look forward to and yet there is little money."

Similar comments were made about stays in respite care where people may have to contribute to its cost and to hospital care where people's benefits were reduced.

- "The lack of money has been a great shock to me - its making me feel unwell - I bought a paper on Monday - it felt like a great luxury."

People repeatedly said that costs could increase when in hospital or respite care either because they had 'double running costs' or, as was more common, because people need to buy items that are not catered for when working out benefits but which can be particularly important when in these situations.

When having a break in respite care, where enjoyment may be particularly important, it may be good to be able to get out and about or to buy the occasional treat. The same applies in hospital when getting into town for a coffee may be a great event or having a cigarette may reduce the tedium or help someone to relax - these things become much harder to get when benefits are reduced.

Another concern was around discharge from hospital – at this critical point in peoples' lives it was strongly felt that people should know that their benefits are those that they are entitled to and that they won't have to worry about this when they get home.

On rare occasions people had lost their accommodation because of hospital stays. This was thought to be wrong.

#### **RECOMMENDATION:**

- The allowance that people get when in nursing homes should be increased.
- People should not have to contribute to the cost of respite care.
- Benefits should not generally be reduced when in hospital for more than 6 weeks.
- People should have a full benefit check before discharge from hospital.

#### **Low Income and Mental Illness:**

Although people didn't think that it was inevitable for people to become ill when on a low income, they did think that there was probably a connection between the two, and that both could reinforce each other to create a downward spiral from which it was hard to escape.

#### **RECOMMENDATION:**

Health interventions should include steps to remove deprivation and poverty.

### **GETTING BACK TO WORK**

There was a strong feeling that while many people with a mental illness have to stay on benefits for a long time - sometimes permanently – they shouldn't because of this feel devalued or pressured to find paid work.

- "People should not be pushed into looking for work when there is no work. This just makes everything stressful for everyone."
- "It is sometimes hard enough to manage let alone think of working. It can be a full time job surviving."

The work or activities that people do should not necessarily be seen as a sign that they can do mainstream work but are often a part of the need that everyone has to feel needed or useful.

Many other people felt, however, that they would be able to work one day but that they faced an uphill struggle to get to the point where there was a realistic chance of getting a job.

There was a strong feeling that many of the employment opportunities that people might have were jobs such as stacking supermarket shelves which were less a reflection of what people could contribute and more of a reflection of the attitude of employers to people with a mental illness.

### **RECOMMENDATION:**

Employers should be encouraged to see the real talents that people with a mental illness have through public education, mental health awareness training and the positive use of the media.

## **HELP WITH BENEFITS FROM ADVICE, WELFARE RIGHTS AND ADVOCACY AGENCIES**

The Citizens Advice Bureaux Network came in for a great deal of praise for the help that they were able to provide.

It was, however, felt very strongly that welfare rights workers should provide clinics in drop in centres and training centres where people feel safe and secure and capable of facing up to the task of claiming benefits.

- "This would be very good. To have help in your environment where you feel safe and there are people around you would be great. It would remove any of the barriers that an outsider may have with helping someone with their benefits."

It is important that there is someone who can guide people through the system:

- "The forms for benefits should come attached to a person. Someone who is local. They will make sure the applicant is happy with filling it in and getting the benefit."

Other people would also benefit greatly from home visits to deal with benefits from people that they trust and who are capable of helping with benefits.

Many people had experience of the Citizens Advice Bureau, (CAB) most of it positive:

- "People can stop claiming DLA because it is so hard, but the CAB can be good at getting it for people who did not get it before."
- "There is one welfare rights worker who is good, but it is hard to get to see her."
- "The solution to any problem with the Benefits Agency is just to use the CAB Advocacy Service and have nothing to do with the Benefits Agency. The Inverness Advocacy Service is very good."

There was however a feeling that sometimes people did not have enough experience of people with a mental illness:

- "The volunteers are good, but are often not too skilled with the sort of problems we come in with."
- "The CAB can be very good but it is often a matter of luck, and like all "staff" there needs to be an awareness of mental health and illness. They often do not understand it, and it is not uncommon for us to get nowhere because when we are in the office we think everyone is looking at us or knows our thoughts or despises us – or because we are so emotional, blunted or upset we can't speak and we mess it up."

There was however a realisation that services were sometimes overworked:

- "The service is mainly voluntary and is getting more and more pressure placed on it, although they are still very helpful. They are held in high regard but need more paid staff...."
- "Access to these is absolutely essential. They are not always easy to access but they can be incredibly helpful."

There is a CAB Advocacy Service at New Craigs Hospital. Whilst people were pleased that it existed and it was agreed that it was very much needed, it also came in for criticism for being so hard to access.

Since these discussions many of the CAB agencies have provided or offered clinics and benefits checks in places such as 'drop in' centres – these have been greatly appreciated.

### **RECOMMENDATIONS:**

- Advice and Welfare Rights agencies should have their role extended through increased resources to include clinics where users feel safe, including in their own homes.
- The Advocacy Service at New Craigs Hospital should be funded to provide a more accessible service.
- Welfare Rights workers and volunteers should have mental health awareness training.

## OTHER ISSUES

### COMMON SENSE

Although a system such as the benefits system needs rules and procedures it should have elements built into it that allow for common sense solutions that, although they may not necessarily fit strictly within the rules, do fit in with the lives of individuals.

An example of this is that there is a limit to the number of hours a person can do in any one week when on training placements for work. However, some people would like to be able to do a full week's placement in order to see if they can cope with this.

#### **RECOMMENDATION:**

There should be flexibility built into the benefits system.

### GETTING BACK ONTO BENEFITS

For some people on certain benefits and in particular circumstances there are fast track methods of getting back onto their original benefits if they become ill again in the first 52 weeks after getting work – this is greatly appreciated but many people do not know that it exists.

#### **RECOMMENDATION:**

There should be wider knowledge of the fact that people can get back onto their original benefits if work doesn't work out.

### OLDER PEOPLE AND CARERS

It was felt that older people and carers had a particularly difficult time when faced by the benefits system.

It was felt that the fact that people over the age of 65 could not make an initial claim for DLA was discriminatory.

**RECOMMENDATION:**

People should not have less benefit because they are old.

**FRAUD**

It was acknowledged that fraud did exist but it was felt that it was easy to catch people who were relatively "innocent " in what they were doing whilst professional "conmen" could evade most attempts to catch them.

It was felt that people committing fraud made the public think badly of all people on benefits.

**ADJUSTING TO THE SYSTEM**

- "Having access to the right help, knowing how to work the system, knowing the right words to use and having the right labels is the best way of getting the maximum benefits. If you know the right phrases you can get the right benefits...."
- "If you are confident you will often get a whole load of benefits that another person won't get"

The benefits that people get should not depend on a person's ability to present a case.

Equally it can be very hard to get used to the system:

- "A lot of people don't know about benefits or of ways of saving money when on a low income."
- "The key to this is acceptance."

**RECOMMENDATION:**

People likely to be on long term benefits should be offered help with budgeting skills if they wish.

## **PRESCRIPTIONS**

If people have a chronic problem such as mental illness then they should get free prescriptions whatever their situation.

### **RECOMMENDATION:**

Prescription charges for medication for mental illness should be dropped.

## **ACCESS TO OTHER SERVICES**

Many activities in the leisure, sports and recreational fields are in themselves very therapeutic. The idea of active prescription and free access and subsidised transport to sports and recreation facilities is a good one.

### **RECOMMENDATION:**

Sports, leisure and travel services should be subsidised for people on a low income.

## **PENSIONS**

There is a growing feeling that the provision of pensions for the whole population is under threat – some members of HUG who know that they will be on benefits for a long time are worried about what will happen when they reach retirement age.

## **PROFESSIONALS**

Many professionals help people with benefit claims – it is important that when they are getting out of their depth that they get proper advice or know where to refer a person onto.

## **BACKDATING**

All claims should be able to be backdated if you can show your situation was the same in the past.



## **RECOMMENDATIONS**

1. The current welfare system remains a vital way to provide for people who cannot work, including those who may be disabled by mental illness. It should remain so.
2. Employees of the benefits system and people determining the direction of the benefits agencies should listen to the views of their clients and make the values by which they operate clear to all.
3. Although illness preventing work is the main reason people need benefits - making employment a viable option through the use of the Disability Discrimination Act and awareness training with employers and helping people to believe in themselves (for instance through schemes such as the Training and Guidance Unit in the Highlands) could reduce the need for some people to remain on benefits.
4. Many people with a mental illness may need assistance to claim benefits which could include visiting them in their homes and providing more publicity about peoples rights to benefits.
5. People need help with understanding that mental illness can be defined as a disability and again may need outreach and assistance in claiming benefits.
6. Benefits agencies need to make every effort to ensure that the stress of making a claim is minimised. The HUG Reports on "Quality" and "Ward Rounds" may be useful guides.
7. There should be a clear guide to benefits for people with a mental illness.
8. There needs to be some rationalising of the information that is provided.
9. Benefits forms should be simple enough for people to fill them in themselves.
10. People need access to assistance in understanding and negotiating the benefits system.
11. Mental illness is a disability. In order to deliver an effective non discriminatory service the Benefits Agency needs to look at the needs of people with a mental illness, including their social circumstances.
12. People applying for DLA should automatically be offered help in making the application.
13. Services should be sensitive to the affect an application can have on a person's mental health.
14. The Benefits Agency should seek to maximise the claims of clients and should take responsibility for any of its mistakes or delays.
15. There needs to be a flexible response to casual work and the extra cost of rural living needs to be included in payments.
16. Benefits Agency staff should have Mental Health Awareness Training as part of their induction and ongoing training.

17. The positive contribution of people on benefits and the reasons that people need to be on benefits should be publicised and the media encouraged to be responsible in its reporting.
18. There needs to be access to funds to deal with sudden changes in circumstances.
19. People should have help with debt management.
20. The allowance that people get when in nursing homes should be increased.
21. People should not have to contribute to the cost of respite care.
22. Benefits should not generally be reduced when in hospital for more than 6 weeks.
23. People should have a full benefit check before discharge from hospital.
24. Health interventions should include steps to remove deprivation and poverty.
25. Employers should be encouraged to see the real talents that people with a mental illness have through public education, mental health awareness training and the positive use of the media.
26. Advice and welfare rights agencies should have their role extended through increased resources to include clinics where users feel safe, including in their own homes.
27. The Advocacy Service at New Craigs Hospital should be funded to provide a more accessible service.
28. Welfare Rights workers and volunteers should have mental health awareness training.
29. There should be flexibility built into the benefits system.
30. There should be wider knowledge of the fact that people can get back onto their original benefits if work doesn't work out.
31. People should not have less benefit because they are old.
32. People likely to be on long term benefits should be offered help with budgeting skills if they wish.
33. Prescription charges for medication for mental illness should be dropped.
34. Sports, leisure and travel services should be subsidised for people on a low income.

## GETTING ACCESS TO INFORMATION AND ADVICE

Within the Highlands there are a number of organisations that can give independent advice on Benefits - some of these are listed below:

<p><b>CAITHNESS CAB</b> 7a Brabster Street Thurso KW14 7AP Telephone &amp; Fax (01847) 894243</p>	<p><b>Wick Extension</b> 123 High Street Wick KW1 4LR Telephone (01955) 605989 Fax (01955) 606673</p>
<p><b>INVERNESS CAB</b> 103 Academy Street Inverness IV1 1LX Telephone (01463) 235345 Fax (01463) 714272</p>	<p><b>LOCHABER CAB</b> Dudley Road Fort William PH33 6JB Telephone (01397) 705311 Fax (01397) 700610</p>
<p><b>NAIRN CAB</b> 6 High Street Nairn IV12 4BJ Telephone (01667) 456677 Fax (01667) 451081</p>	<p><b>ROSS &amp; CROMARTY CAB</b> 4 Novar Road Alness IV17 0QG Telephone (01349) 883333 Fax (01349) 884126</p>
<p><b>COMMUNITY ADVICE &amp; INFORMATION SERVICE (Badenoch &amp; Strathspey)</b> 85 Grampian Road Aviemore PH22 1RH Telephone (01479) 810919 Fax (01479) 811058</p>	<p><b>EAST SUTHERLAND VILLAGE ADVISORY SERVICE</b> Alba Main Street Golspie KW10 6TG Telephone (01408) 633000 Fax (01408) 633000</p>
<p><b>SKYE &amp; LOCHALSH CITIZENS ADVICE BUREAU</b> The Green Portree IV51 9BT Telephone &amp; Fax (01478 612032) E-mail: info@skyeAdvice.co.uk</p>	<p><b>NORTH WEST SUTHERLAND ADVICE &amp; INFORMATION SERVICE</b> Office 3 Harbour Offices The Pier Kinlochbervie IV27 4RP Telephone &amp; Fax (01971) 521730</p>

The Scottish Association for Mental Health also has an Information Service that can pass people on to organisations that also give independent benefits advice. Their telephone number is :

0141 568 7000

Monday Wednesday and Friday

11.30am – 4.30 pm.

## **ACKNOWLEDGEMENTS**

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

For more information about HUG, or an Information Pack, call:

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