OCCUPATIONAL THERAPY

A Focus Group discussion by members of the Highland Users Group on behalf of the Sainsbury Centre for Mental Health and their work developing a strategy for Occupational Therapy for the College of Occupational Therapists.

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WHAT IS HUG?

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

At present, HUG has approximately 360 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

In November 2005 HUG was approached by the Sainsbury Centre for Mental Health to run a focus group of people with a mental illness in the Highlands. They had been commissioned to develop a strategy for Occupational Therapy services across the U.K. and wanted to hear from members of HUG.

They wished a service user, who could also be an advocacy worker, to facilitate a group of HUG members to discuss 8 preset questions and then provide a report on the findings of the group.

The ideal group size was set at about 12 people who should be from as diverse a community as could be managed.

They provided an introductory letter, a project brief, a series of questions, and a statement of principles and vision. (The vision and the questions were sent out to HUG members in advance of the meeting.) They paid all the expenses of the HUG participants and an honorarium of £25 to participants in recognition of the contribution they were making. They also provided a fee to HUG for the work carried out.

The HUG members were recruited from the HUG Friday Forum, a working group of active HUG members mainly based around Inverness and from the HUG Round Table, the HUG committee. This was because places were limited.

On the day, 11 out of the 14 people who wanted to attend did so. Five of the participants were from Inverness and the rest were drawn from Caithness, Easter Ross and Badenoch and Strathspey.

The approximate age range of participants was between 30 and 60. There were 6 women and 5 men. There were no people who identified themselves as being from an ethnic minority or from the gay, lesbian or transgender community, although no one was asked this question directly. None of the participants were currently in full time employment although most had in the past. No one had any visible disability. There was one single mother, a number of other parents and around half the people were currently single. Nearly everyone had direct experience of occupational therapy and one person had also experienced occupational therapy for a physical problem. Nearly everyone had experience of hospitalisation for a mental

illness and the conditions people had experienced varied from schizophrenia, depression, manic depression, anxiety, Bulimia and addiction, to post traumatic stress disorder and personality disorder.

The focus group started off with a sandwich lunch (4 of the participants had travelled 120 miles to attend the meeting) and was followed by a presentation by two Occupational Therapists about what occupational therapy is. This prompted discussion and many questions which the Occupational Therapists played a part in before they left, and the prepared questions were addressed over the next two and half hours.

The questions had been adapted a little in advance of the meeting as they were not thought to be as accessible as they could be. They were further adapted in the meeting according to the sense we could make of them.

Notes were taken of the meeting and then converted into this report which was sent out to the HUG participants to check that they were happy with it and to allow any comments to be added if they wished. Some other HUG members who used occupational therapy services also saw the report and added some additional comments.

The group felt that the discussion was so interesting that they decided to ask for the final document to be used locally for their own service. Our thanks are due to the Sainsbury Centre for Mental Health and the College of Occupational Therapy for allowing this to happen.

WHAT DO WE MEAN BY OCCUPATION?

Occupation had many meanings for us. Being occupied can keep us well especially when we feel that what we have done is productive. Achieving something can prevent illness. If we do things with no end result then we can feel that what we are doing is done in vain and may question why we did it in the first place.

This isn't the case for everyone; some of us have led lives that concentrate on all occupation leading to success and a result for those of us in this situation is learning to do things just for the pleasure that they give. This can be as important as any tangible achievement.

Doing things increases our sense of self worth. If we have nothing to do then we can become very isolated and this works against us. Some of the things we do and benefit from, such as music or singing have no tangible benefit, but leave us feeling invigorated and happy.

The same applies to physical activity. This increases our sense of well-being and improves our mental health. Many of us feel that physical and mental health are closely entwined and that we need to respect both. This influences how we feel about ourselves. If we neglect either of these we can lose out.

Creative occupation is very important to some of us but we can need a catalyst to stimulate creative activity.

Occupation can be very simple; having a structure to our day or a daily routine can make a big difference to us.

Equally, occupation is not just about activity, for some of us the chance to take up paid employment is a fundamental part of how we want to spend our time. Apart from payment it also increases our sense of dignity and self worth.

Sometimes it is not so much about activity, it is also about being with other people: *"talk together learn together"*

Also, when we sit around and have nothing to do, we feel that we are more likely to become ill.

OCCUPATIONAL THERAPY AND ACTIVITY

We felt that there is a distinction between occupation that is a part of therapy and the occupation that is just everyday activity despite the fact that both help with our well-being.

Some of us lose the ability to do ordinary activities when we go through illness and may need some re-education about our lifestyles.

The intervention of Occupational Therapy can help give us a language that we can use which helps us understand the benefits of the things we do.

It has many other aspects; it may help us to laugh and enjoy ourselves but equally it may help us create an ordinary routine which may seem simple but is a big step for some of us. For others it can give us the skills and motivation to look for paid employment. It can also help us with our feelings; it may help us see the funny side of life or gain the ability to cope with failure.

We need to be sure that when we start Occupational Therapy that it will suit us as individuals; it has to have a diverse approach in order to achieve this. If we are to engage with it, it is important that we do things that we want to do. These are often things that we are good at or enjoy.

It is also important that it strikes a balance between helping us regain the ability to resume the skills of everyday living without us feeling that we are being patronised or asked to do tasks that are over-simplistic. This needs to be matched with helping us to do things that we can succeed at and yet at the same time not creating a pressure to succeed that we can't live up to.

It can open up new opportunities by exposing us to new situations and help us find a voice and means of self expression that we lost when we became ill.

WHAT SHOULD OCCUPATIONAL THERAPISTS DO?

We had many ideas about what we thought Occupational Therapists can and should do. These were varied but included the following:

We thought that many professionals concentrate on the problems and conditions that we face but that Occupational Therapy can and should help us achieve a balance in our lives by treating us holistically and addressing mind, body and spirit.

We wanted them to help us sort out negative thoughts, to provide activities that promote inner peace and to quieten our minds and ultimately to remove us from some of our internal pain.

We felt that their role in rehabilitation was very important (especially if we also have physical problems.) and that the activities they could help us with included helping us find activity, helping us to do stuff purely for the fun it involved, increasing our well-being and helping to re-integrate us back into our communities.

We felt that they could play a big role (maybe vital) in the process of recovery and had a role in *"kick starting your mind into recovery and occupation."* This involved helping us find our own pathway in life and helping us learn the skills that would allow us to look after ourselves.

We wanted them to provide distraction from the feelings that we experience, especially in hospital but also outside in the community. We wanted them to help us look at what our experience might mean to us and made it clear that we regard occupational therapy as more than activity but included 'passive' acts such as relaxation. We felt that they were in a position to look at a wide range of non-medical interventions which nevertheless would have a great impact on our well-being.

We wanted them to provide us with the ability to get out of the world of mental illness and back into the environment we wanted to be in:

"Teach me the skills to look after me, help me do the things I like doing."

THE CORE WORK THAT OCCUPATIONAL THERAPY SHOULD BE DOING

We were given a list of the different roles that Occupational Therapists have and were asked to prioritise them.

We did this by each of us giving the different roles a score between 1 and 8 and then adding up the scores to a total from our group. The results that we ended up with provided the following scale of priority:

1. assessing occupational needs and functioning (most important)
2. improving quality of life
3. promoting health and preventing disease
4. preventing or alleviating disability
5. improving functional ability
6. promoting social participation
7. increasing access to occupation including employment
8. community development (least important)

HOW OCCUPATIONAL THERAPY HAS HELPED US

We looked at some examples of how we have been helped by occupational therapy. These included:

a) Writing groups

5 or 6 of us met each other weekly and helped each other out – it helped me a lot.

b) Art

This was good it gave me a focus and something to look forward to in a dark time. It provided an escape and helped me feel healthier and better.

c) Physical activity

Even walking was a major effort. I was just vegetating, the staff provided the spark by saying that I needed to start to help myself. They rattled my cage and I went to the gym. Having physical activity stops you getting worse and helps you out - it has a lasting effect.

d) Gardening

This was amazing - we started out as a diverse and separate group of people and ended up pulling together.

e) Assertiveness training

It helped me with the feelings I had and with meeting a group of people in a similar situation.

f) Woodwork

I got a lot out of it - it was something to do as well as a safe environment with a sense of achievement when you had completed something.

g) Dress-making

I learned dress making and ended up dressing myself. It was a good feeling and something that I kept on doing afterwards.

h) Picture framing

This was a very popular activity. We learnt picture framing free of charge and framed our own art. It encouraged us to feel a pride in our success. I really enjoyed it.

i) Physical problems

This was very different. I learnt to go out and walk again. It was very hands on.

j) Pottery

I had never done it before. I enjoyed it. When I was discharged I looked for more opportunities to do pottery and found an organisation with a rarely used pottery which I used. I ended up teaching pottery to others and would now like to work in this field. It helped me find an activity, to reach my potential and to, in turn, empower other people.

The examples given here range from very recent or current activities to those which occurred 40 years ago. They included occupational therapy in hospital as well as in the community and are just a small sample of activities undertaken.

A number of other comments were added after this group reported back. These included:

It helps us learn new skills.

We find out tips that we can pass on to each other.

It gives security because we are all part of a team that understands the difficulties we all face.

We feel a sense of security as even when we only attend sessions occasionally we are still made welcome.

Fellow patients are often the first to pick up if we are getting into difficulties. In this way we act as an "early warning system" for each other.

O.T. is very helpful - it can be as important to us as remembering to take our medication.

WHERE SHOULD PEOPLE BE ABLE TO ACCESS OCCUPATIONAL THERAPY?

This area of inquiry opened up a wide ranging discussion in which we came to feel that the services that an Occupational Therapist could offer could be of benefit to the well-being of a great number of people not just people with (generally severe) mental illness.

The places that we wanted to see occupational therapy apart from the hospital included:

- G.P. surgeries
- Sports centres
- As a part of evening classes
- As part of the teaching of the Workers Educational Association
- In libraries
- In colleges
- As part of community education
- Via the internet
- Based in community mental health teams
- In village halls
- In drop-in centres
- In mental health and employment projects

However the discussion then turned back on itself a little. We initially thought that occupational therapy could expand greatly and include a much wider client base to everyone's benefit. However we were also aware that this might not be possible in times of limited resources and were keen to make sure that it remained available to people with a mental illness. We need to protect our specialist services as they are vital to many people. There are also many people with a mental illness who do not receive occupational therapy but could benefit from it and should be able to access it.

Many of these people live in the community and should be able to access the service near to where they live.

We were disappointed that occupational therapy can help us a great deal when in hospital but that on discharge many of us had no access to occupational therapy, either because we weren't referred to it or because it wasn't available in our communities.

We felt that access to occupational therapy was very important in the transition period between hospital and home.

We thought that other organisations apart from the health service and social work could usefully employ Occupational Therapists.

We also thought that we should aim at prevention. We remembered pictures from the television showing people in China doing exercises before work. Why don't we do this? We talked about the fact that mental illness is one of the biggest causes of absence from work. Why don't employers employ Occupational Therapists to work in the workplace before we lose our jobs due to ill health?

THE SKILLS AND ABILITIES OF OCCUPATIONAL THERAPISTS

We discussed this and came up with a number of different but maybe complementary suggestions.

Many of us felt that Occupational Therapists could play an important part in the talking therapies (such as Cognitive Behavioural Therapy) that we can find so much difficulty in accessing. We wanted them to have enhanced skills in this area and thought that their approach may be very useful to many of us.

Some of us saw the skills that they could offer in a different light:

"*It could be easier if they didn't know what our mental illness was in the first place. It might make it easier for us to feel that we are being treated as a person distinct from illness. They did that with me, not me the patient, but me that I am.*"

Some of us felt that if we are concentrated on as people with an illness then it distorts how we are seen and treated.

We need them to offer us a range of opportunities and tools to help us develop.

We felt (especially in the community), that Occupational Therapists could be asked to provide such a varied range of activities that there would be no chance that they could possess all the skills needed. However we felt that if they had the ability to approach other professionals or organisations to fill these gaps then they would enhance the service that they could offer us. It's not necessarily the skills themselves that they need but the ability to find and promote them:

" *They don't have to be an artist to help us with self expression, help us to see and guide us to the solution and help to inspire us.*"

These skills can be hard to quantify:

"It can be like piano tuning; some have a better ear than others"

"It's a sense that tunes into our needs and feelings even when we can't speak."

We wanted Occupational Therapists to be able to offer us a range of opportunities that suit us as individuals and which we could try out. These could be group work or one-to-one sessions and may open up alternatives that we weren't aware of. Some of us need a chance to develop core skills and need to learn new ways of expressing ourselves. The Occupational Therapist will probably not be able to provide all this but they may be helpful in guiding us to the right place. Many of these skills could be especially important in community settings.

Many of the skills that they need to demonstrate are about how we are approached:

"In hospital you can just want to be left alone; you need to be able to pick up on the past and to be able to join in."

"We need to be approached gently."

"Occupational therapy is about mind and body; we need to see that."

We felt that occupational therapy involved many skills and that although a medical grounding was important, that helping us with social skills was also very important.

We thought that Occupational Therapists should start off their training as generic Occupational Therapists and once they have completed that they should have the opportunity to train further in specialist areas such as mental health (perhaps as part of a postgraduate degree.)

Some of the skills that we thought they should have were:

- A knowledge of Information Technology and how it can be used
- Communication skills
- Listening skills
- Interpersonal skills
- Compassion
- Empathy
- Dealing with aggression
- Lifting and handling

- Humour
- Practical skills
- Safety (providing it)
- Group work
- Side effects of medication
- Background knowledge of medical treatments
- Awareness of what mental illness is like
- Dealing with distress
- Being able to find out what we want.

We became aware that this list could be limitless so decided to stop there.

HOW DIVERSE ARE THE BACKGROUNDS OF THE OCCUPATIONALTHERAPISTS THAT WE SEE, AND HOW COULD RECRUITMENT BE IMPROVED?

We felt that they were mostly women and mainly in their thirties. We knew of one male Occupational Therapist in the Highlands. (We found out later that we were not fully accurate : the age range is wider and there are three male O.T.'s)

We considered whether they should be more reflective of wider society especially of different ethnic minorities. In the light of the fact that there is now a rapidly growing East European population in the Highlands we thought that the Occupational Therapists should make their service as accessible as possible for instance by addressing language barriers. However we thought that it was not essential for the workforce to be racially diverse, what was important was that anyone, whatever their background, should be able to use occupational therapy without experiencing barriers to this. However, it should be noted that no one in the group considered themselves to be from an ethnic minority and that may influence our thinking.

We felt that it was hard to get employed as an Occupational Therapist in the Highlands and in addition that recruitment was a problem, that it was common to lose staff from remote areas and also that there was a shortage of Occupational Therapists generally.

Solutions that we had to this were:

- Improve the recruitment advert – it doesn't grab people's attention
- Make the job attractive
- Stop unnecessary bureaucracy attached to the job
- Make them feel valued
- Make them feel as important as other professionals
- Pay them more
- Make it a distinct and rewarding profession
- Make it a vocation
- Get Occupational Therapists into schools so that children might consider it as a future career
- Get the government to intervene and take some responsibility in helping make occupational therapy more attractive.

WHAT IS THE PROFILE OF OCCUPATIONAL THERAPY IN GOVERNMENT POLICY?

None of us were aware of any major government policies that gave a high profile to occupational therapy, although we did hear that it had a small mention in the Mental Health Act.

We felt that occupational therapy was on the margins in this area and needed to have greater impact and a more visible voice.

We felt that users should add their weight to expressing how important occupational therapy could be and that this pressure may result in greater access to an important service.

It needs to have a higher profile in Government, in policy and with the public and we feel that user groups should be consulted more about the direction of occupational therapy and the value we get from it.

OTHER ISSUES CONNECTED TO OCCUPATIONAL THERAPY

Roles
We felt that professionals could learn from each other, that they often have a range of skills on offer that could be used to benefit patients irrespective of what professional background that they have. We also felt that different professions should encourage links with each other and that they should tap into each other people's differing expertise.

We are sometimes surrounded by many professionals. When discussing our care, we need continuity, not lots of different people.

We felt that other professionals needed help to see the value of occupational therapy.

Transition
We need links between hospital occupational therapy and community occupational therapy especially around the time of discharge.

Community Occupational Therapy
Although the help we get in hospital is very important, so is the help we get in the community. Some of us are in areas where there are no Occupational Therapists at all. We think this is wrong, and feel there is a need for an enhanced community occupational therapy service that we can access easily. Some of us have had to travel long distances to access occupational therapy which we don't think is acceptable.

We felt that we should be able to access occupational therapy in day centres and in drop-in centres. Occasionally it seems like little happens in these places. Occupational therapy could help improve this.

Some of our members, on reflection, felt that the importance of community occupational therapy needed more emphasis – for those that receive it, it is very very important and for those that don't it can be sorely missed.

Image
Many of us have limited understanding of what occupational therapy is. It is often seen as less of a therapy and more of a way to fill our time when we have nothing to do.

The leaflets that are provided about occupational therapy are also out of date. However when we are ill it can be very difficult for us to take in explanations about what occupational therapy is, or to realise that activity can be therapeutic.

It can take some time before we realise how valuable occupational therapy can be.

Hospital Occupational Therapy
We had some mixed feelings about this. Some of us said that structured activity can be very important (especially in hospital) whilst others said that when we are first admitted that the opposite was the case. What we need is the room to do things (it doesn't always matter what) in our own time:

"*Do something for me and then build on it.*"

We felt that despite the benefits of structure, that it could inhibit spontaneity.

Many of us had had very good experiences of occupational therapy whilst in hospital but felt that, despite this, we didn't always know what it was, what it provided, or what we could expect from it. We also felt that access often depended on knowing about it first. If we knew that it existed, then we were much more likely to get access to it than those of us who had little or no knowledge of it.

We felt that there was not enough access to occupational therapy in hospital and that access to it was not always fair.

We felt that Occupational Therapists should be involved in ward rounds if patients wanted and that we needed more chances for one-to-ones and space to talk with them.

We felt that in some ways the role of an Occupational Therapist could be as important as that of our primary nurses.

However some of us have felt pressurised to use occupational therapy when we are 'in patients' and feel that this can defeat the purpose of it, especially when we are feeling very delicate.

We felt that the locked wards of hospitals had a great need for occupational therapy input, but our impression was that this facility was not available at present. Occupational therapy can feel like our only link with the outside world when we are in a secure ward and is very important.

We felt that having open occupational therapy sessions on the ward was good, as they allowed us to participate in our own time and at our own pace. Equally, if we found them too much then we could easily escape.

We did feel that it was important that we didn't have to feel that we had to do occupational therapy. It should be something we want to do.

The Occupational Therapy Base
We had some ideas for this that didn't fit completely together:

We felt that:
- Occupational therapy should be based in the community and go into hospital.

But we also thought that:
- Occupational therapy should be based in the hospital wards themselves.

We felt that we need both of these things depending on where we are ourselves at the time.

Access
We felt that occupational therapy can be very approachable and is "*there for you*". We also felt that Therapists are good at respecting difference and eccentricity that they don't categorise us and, whilst providing therapy keep this in the background.

We felt that ideally, the general public should have easier access to the sort of service that occupational therapy can provide as long as this doesn't mean that the service is diluted to the extent that it stops being valuable to those of us who already use it. However we also thought it

should be made accessible to anyone with a mental illness who could benefit from it as this is not the case at present. We also thought that we could all benefit if there were better links between occupational therapy and the voluntary sector.

The value of occupational therapy
Many of us have had very good experiences of occupational therapy:

" *Your role in life can be devastated. Occupational therapy can help you re- evaluate your life."*

"Occupational therapy saved me in my darkest moments."

"Occupational therapy re-ignites your hope and helps you realise your dreams are possible when everyone else is dismissing them."

The wider role
We need to show that the Occupational Therapy Service is something that helps with life skills and could be helpful to a wide range of people.

Occupational therapy assessments
There was a feeling that the questions that were asked as part of an assessment could be intrusive and off-putting. However not all of us felt that way:

" *They asked a lot of questions but they were great. They helped me to describe myself in a new way."*

Success
We wanted success stories in occupational therapy to be highlighted.

Mental well-being
We felt that its role in mental well-being also needed to be highlighted alongside the help it provides with mental illness.

The name
We felt that the name "occupational therapy" wasn't descriptive enough. Perhaps it could be changed. A few suggestions were:

lifestyles therapy, life skills therapy or life coaching.

CONCLUSION

We feel that the content of the report is self explanatory but generally we have found occupational therapy both in the hospital and in the community, in the distant past and the present, very helpful.

We feel that there is a shortage of occupational therapy in many areas but especially in the community and feel that the skills of Occupational Therapists, despite already being broad, could be usefully expanded to include talking treatments and the development of an approach that can include partnership with other professionals or the ability to help us learn our own skills and solutions.

We are concerned that occupational therapy is not recognised sufficiently and is not mentioned (as far as we are aware) as anything more than an add-on in many policy documents.

Rather than a long conclusion the participants of the workshop wanted us to close with a quote from the statement of vision that the Sainsbury Centre for Mental Health provided us with:

"Occupation is seen as a human right and occupational deprivation a violation of human rights."

ACKNOWLEDGEMENTS

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

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