# Recovering Ordinary Lives

## The strategy for occupational therapy in mental health services 2007–2017

*Results from service user and carer focus groups*

College of Occupational Therapists

College of Occupational Therapists

## About the publisher

The College of Occupational Therapists is a wholly owned subsidiary of the British Association of Occupational Therapists (BAOT) and operates as a registered charity. It represents the profession nationally and internationally, and contributes widely to policy consultations throughout the UK. The College sets the professional and educational standards for occupational therapy, providing leadership, guidance and information relating to research and development, education, practice and lifelong learning. In addition, 11 accredited specialist sections support expert clinical practice.

College of Occupational Therapists

**www.cot.org.uk**

By 2017, mental health service provision in the United Kingdom will be better for the active role and inspirational leadership provided by the cultural heritage and identity of occupational therapy, which at its core is social in nature and belief and, therefore, will deliver the kind of care that service users want, need and deserve.

 This photograph was produced by a mental health service user for the strategy. The picture symbolises her journey through mental illness to recovery. The glass bowl represents the constraints of her mental illness; she can see the world but can't access it, be a part of it. Through the intervention of occupational therapy she is able to grow, break free (symbolised by the broken twigs), quite literally escape, join the world and leave her illness behind.

# Recovering Ordinary Lives

*The strategy for occupational therapy in mental health services 2007–2017*

*Results from service user and carer focus groups*

College of Occupational Therapists

**Core**

College of Occupational Therapists

The College of Occupational Therapists, 106–114 Borough High Street, Southwark, London SE1 1LB
www.cot.org.uk



First published in Great Britain in December 2006 by the College of Occupational Therapists.

This document should be referenced as:
College of Occupational Therapists (2006) *Recovering ordinary lives: the strategy for occupational therapy in mental health services 2007–2017, results from service user and carer focus groups*. (Core.) London: COT.



Typeset by Servis Filmsetting Ltd, Manchester.
Printed and bound in Great Britain.

For free distribution only. UK applicable.

## Contents


| | | |
|---|---|---|
| **Section 1** | **Results from the Highland Users Group (HUG)** | **3** |
| **Section 2** | **Results from the Black and Minority Ethnic Group (BME)** | **19** |
| **Section 3** | **Results from Carers in Partnership, West Midlands** | **27** |

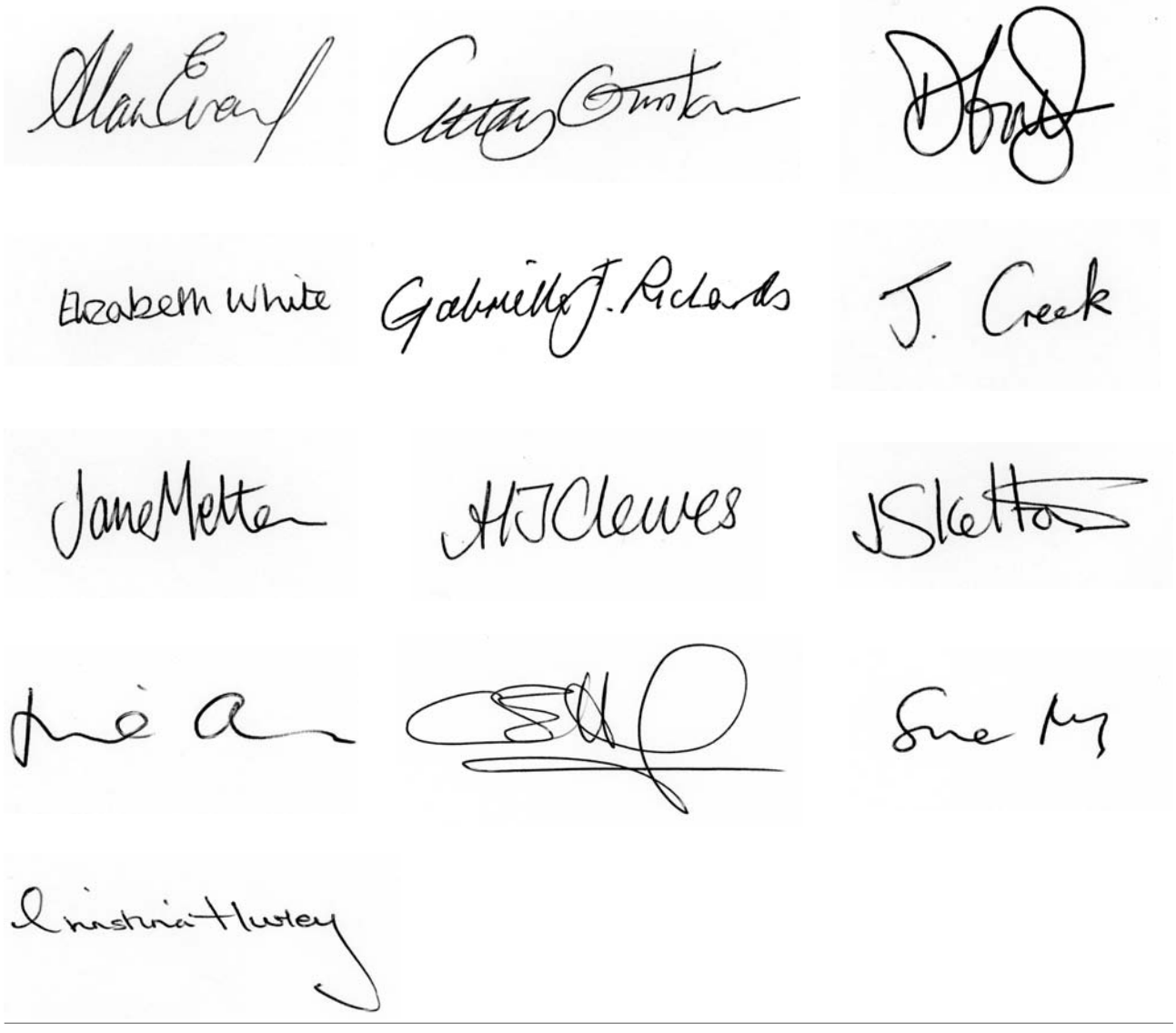
## Introduction

As a part of developing and delivering *the strategy for occupational therapy in mental health services*, the Sainsbury Centre for Mental Health (the project team) involved service users and carers in the consultation process.

The steering group responsible for the strategy unanimously felt that their contributions are so important to the process that they should be included in this suite of documents.

We the undersigned (the members of the steering group) proudly present this document to its readers and in doing so are acknowledging the high quality of their involvement. We wish to thank all the people who gave their time, effort and expertise.

From us all – thank you



# Section 1 Results from the Highland Users Group (HUG)

Date: January 2006

The following is a report from a focus group discussion by members of the Highland Users Group (HUG) on behalf of the Sainsbury Centre for Mental Health as part of their work in developing a strategy for the College of Occupational Therapists. The text has been reproduced as submitted, apart from minor style changes.

For more information on the Highland Users Group, or an information pack, please contact Graham Morgan, Highland Community Care Forum, Highland House, 20 Longman Road, Inverness IV1 1RY; telephone: (01463) 718817; fax: (01463) 718818; email: hug www.hug.uk.net

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

HIGHLAND USERS GROUP
HUG
ACTION FOR MENTAL HEALTH

## Highland Users Group (HUG)

**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 305 members and 13 branches across the Highlands. HUG has been in existence now for nine 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 the Highlands who have experienced mental health problems;
- to promote the interests of people in the Highlands 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 mental health problems;
- to participate in the planning, development and management of services for service 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 groups and interested parties;
- to increase knowledge about resources, treatments and rights for service users;
- to promote cooperation between agencies concerned with mental health.

**Introduction**
In November 2005 HUG was approached by the Sainsbury Centre for Mental Health (SCMH) 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 UK 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.

SCMH 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.)

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 six women and five men. There were no people who identified themselves as being from an ethnic minority or from the gay, lesbian or transgender communities, although no one was asked this question directly. None of the participants were currently in full time employment although most had been 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.

A presentation was made 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 a 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 our own service. Our thanks are due to the Sainsbury Centre for Mental Health 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 wellbeing 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 wellbeing.

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 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 wellbeing 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 including '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 wellbeing.

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:

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

**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.'*

**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.'*

**Gardening**
*'This was amazing: we started out as a diverse and separate group of people and ended up pulling together.'*

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

**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.'*

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

**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.'*

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

**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 that 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 they 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*.'

'*OT 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 enquiry 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 wellbeing 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, 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 occupational therapists 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 OTs.)

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 [to the fact] 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 audible voice.

We felt that service 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 service 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 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, 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-valuate 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 wellbeing**
We felt that its role in mental wellbeing 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.'*

# Section 2 Results from the Black and Minority Ethnic Group (BME)

Date: 17 January 2006

The following is a report from a focus group discussion by members of the Black and Minority Ethnic Group on behalf of the Sainsbury Centre for Mental Health as part of their work in developing a strategy for the College of Occupational Therapists. The text has been reproduced as submitted, apart from minor style changes.

For further contact information contact the Sainsbury Centre for Mental Health, 134–138 Borough High Street, London SE1 1LB

## Black and Minority Ethnic Group (BME)

Inspire and Influence (I&I) is an independent offshoot of the Breaking the Circles of Fear team and is a national Black mental health service users' network. I&I members were used for the focus group.

BME service users were asked to be part of this focus group in order to share their experiences of using occupational therapy. The group comprised five individuals: two males, aged 36 and 41 years and three females, aged 35, 46 and 47 years. The ethnic origins of the participants were as follows:

African Caribbean – 1
African – 2
African British – 1

The other person withheld this information.

The first two questions were posed in order to get a general feel for the individuals' experience of using occupational therapy and to explore the role of an occupational therapist.

**1. What has been your experience of using occupational therapy?**
The overall experience of most of the respondents was a negative one, with the activities being offered seen as being irrelevant, not connecting nor reflective of the current situation that they were at the time experiencing, whether it was that of being unwell in the hospital or unwell in the community.

*'It was not relevant to me: baking fairy cakes and cooking English meals and playing the drums were not relevant to me . . . I felt my life was passing me by.'*

*'Painting and group work was done, but I felt that it was just a way of putting me somewhere.'*

*'My first experience of using OT was as a child . . . Back then I did art and played with other children. As an adult, they could not offer the sort of therapy I wanted. I felt like a child again.'*

There was one positive experience. Here the difference was that the respondent and her OT worked together in partnership and this took place in the community, however she did go on to say that after a while the work programme became too repetitive.

'*. . . When I came out of hospital, I did a lot more with my OT. We worked together to do a daily programme of how to cope on my own. It was ok, but then it became too repetitive, so then I filled my time with other things that I liked, like going to Church and the gym.'*

**2. What in your opinion is the role of an occupational therapist?**
*'If you're in hospital it's to be the link person to the community.'*

*'To help make that transition from the hospital to your everyday activity, this could be cooking, physical exercise . . . It means having the resources in the community so that you can function in the community*.'

*'To give you activities that are designed to help to build you up emotionally and help you to be independent*.'

*'To look at your way forward for the future*.'

*'To explore what the individual can do, given the nature [side effects] of the medication*.'

*'Depends, which one, can be a foot OT, OT for work. The word OT is a big word and is confusing, especially to mental health service users*.'

*'OTs are supposed to be involved in community development. For example, if you wanted the Church community to work more effectively with people with mental health issues, then the occupational therapist would go in there and do an assessment of all the activities that the place does, and look at the PA system etc. and develop a programme around the activities of what the Church is already doing and then give them the support to carry this out. So they are doing an assessment of what exists, and of what the person is already involved in, and helping the individual to get back into what they were doing*.'

**3. In your view, how does 'occupation' impact on mental health and wellbeing?**
Here, there was some confusion around the meaning of the word 'occupation.' Some saw the term as work; others saw it as occupying time and space. While others said that it did not relate to them or their outside life therefore there was little impact in relation to their mental health or wellbeing.

*'I hated it especially when I recognized that whatever work I was doing was being used to judge my wellness*.'

Here the individual felt that if they painted a picture black then this information would form part of their assessment and be fed back to the psychiatrist. This then created a lack of confidence and confidentiality with their OT.

*'When you are not well and someone talks about occupation, it can be seen as aggressive*.'

'*The term occupation is very general. It can be seen as how you occupy your time – so are the therapists there to help you occupy your time?*'

We can see that the role of an OT needs to be clearly defined. For some it is only linked with work or employment. In general, it was felt that the word 'occupation' as affiliated to 'occupational' therapy could be seen as misleading. As one respondent put it;

*'After using the system for a long period of time, I still don't know what an OT is or what they do. But if the name was changed for instance to a 'Wellbeing Partner' then that would give a clearer understanding. We all know what roles a GP or a dentist specializes in, but an occupational therapists: what exactly is it?'*

**4. What do occupational therapists do and how do they do it? What makes their work distinctive or unique if at all from other clinicians?**

Answers given included:

*'To promote health and prevent disease.'*

*'They have the most scope to be creative, but it's always around their own agenda.'*

*'They are unique in the sense that they work around an individual, even though their work is the same, it is tailored to the individual.'*

*'Their jobs need to be more clearly defined.'*

Here it was felt that occupational therapists are unique in their flexibility to be creative and that this made them unique from other clinicians.

**5. Occupational therapy in mental health exists at many levels e.g. specialist support workers, senior practitioners etc. and in several locations e.g. assertive outreach, community mental health teams etc. Their role could include:**

- **Assessing occupational needs and functioning.**
- **Promoting health and preventing disease.**
- **Preventing or alleviating disability.**
- **Improving functional ability.**
- **Increasing access to occupation, including employment.**
- **Community development.**
- **Improving quality of life.**

**Which of the seven items do you think describes the core work that occupational therapists should do? Prioritise them with the ones you feel are most important first.**

Responses given were:

1. Improving quality of life.
2. Assessing occupational needs and functioning.

3. Community development.
4. Improving functional ability.
5. Promoting social participation.

A clear first was improving quality of life. Community development was also seen as a must if individuals were to be settled into their community effectively. OTs must be visible in the communities and likewise be active in bringing awareness to the communities. It transpired that most of the participants were unaware that the list given was inclusive of the role of an occupational therapist.

**6. Where is occupational therapy in mental health successful (beyond the public sector)? Should the profession encourage and support this work?**

Occupational therapy in mental health works in the private sector. It was felt that the role of an OT was more clearly defined in the business sector, especially in promoting a healthier working environment. This includes providing specially designed chairs, which helps individuals with their posture. Their focus is on productivity and not on inability. It was agreed that the profession should encourage and support this kind of work. Additionally, visiting local community groups and doing more preventative training, as well as promoting wellbeing in schools to raise the profile of the OT's role, should also be encouraged.

A comparison was made between the way assessments are done with those with physical and mental health challenges . . .

*'. . .With physical disabilities, they seem more ready to access resources, and analyse situations. In mental health there is a big divide between the role of the OT for those with physical disability and mental health. Same character content, but the delivery to each of these client groups is different. For instance, OTs when working with physical disabilities are more likely to go around to the home and do assessments, putting in ramps and adapting bathrooms, the list goes on and on. In my ten years of using mental health services, I have never had one come round my home. Everything was based in a group setting. OTs are not outward looking.'*

**7. Do you feel that (a) the basic educational training in mental health and (b) Continued Professional Development opportunities for occupational therapists is appropriate? If not, what changes would you make? E.g. training in CBT or Solution Focused Brief Therapy Workforce. Does the workforce need to be more diverse to deliver better services? If so, how should this change?**

The respondents felt that both the basic education and training in mental health and the professional development opportunities that currently exist for occupational therapists are inappropriate, as it is felt that the training that the OTs have received is similar to that of the psychiatrist, which comes from a Euro Centric perspective, therefore the needs of Black and minority ethnic groups would not be met. Some felt that OTs did not need to have mental

health training whilst others did. There was a consensus that, OTs should be trained by those who have themselves used services and that it is imperative that the occupational therapy workforce have an understanding of the people who they are working with and have a willingness to learn.

Training in the area of Solution Focused Brief Therapy and Employment Support in the Black community should be addressed from their perspective.

'*We need someone who is trained in Black and minority ethnic issues and understand where they are coming from and their perspectives. This would be helpful. But if they are coming from a mental health perspective, then this would not be helpful.'*

*'They need to be concerned about how people live together rather than how people work together, and spend more time with practical stuff on the ground with the community, rather that with clinical stuff and with the hospitals.*'

**8. How diverse, in terms of gender, race, range of skills and capabilities, reflective of local population etc., is the occupational therapy workforce? Does the workforce need to be more diverse to deliver better services? If so, how should this change?**

All were in agreement that OTs were usually the same . . . '*Usually a young white middle class girl*' and felt that the workforce needs to be changed as it is not reflective of the local population or of clients' needs.

Some of the suggestions that were made were:

- Input of service users into the training of OTs, as this is the only way that they will know the needs of the service users.
- They should help people live in the community and as a starting point help them to discover their purpose.
- OTs should include a pool of counsellors to avoid the waiting list.
- OTs should have skills that include promoting health and illness prevention.
- They should be more sensitive to individual needs.
- A new curriculum, a new approach to training needs to be initiated.
- Redefine the purpose of OT so that everyone understands who they are.

**9. How visible is the occupational therapist in the government's mental health agenda? How can it be made more visible?**

Each participant agreed that occupational therapy is not visible at all in the government's mental health agenda, and that it needs to be.

'*We are aware of the new mental health bill, but have no knowledge of the government's mental health agenda.*'

Suggestions for it becoming more visible were as follows:

- promoting good practice;
- taking on board the voice of the service user.

**10. Please share with us any other areas you feel we need to consider in the development of a ten-year strategy for occupational therapy.**

Respondents had much to say about the way that the occupational service could be improved and developed over the next ten years. All felt that the service was not working in its current format, as it often gave little or no resolve to the needs and/or recovery of Black and minority ethnic service users. What became very apparent is the need for OTs to have a clear role and service users should be able to shape that role.

The sense of community was a very common theme that followed throughout the consultation. Being able to work with families and understanding people's spirituality were deemed important. Respondents said that individuals need to be both prepared for returning to their community and assisted while in the community. Community development that involves raising awareness, and finding out those things of interest and importance to the individual was vital. This includes involving the family, the Church and other community networks and faith groups.

Thus the areas that should be considered when developing the ten-year strategy for occupational therapy are as follows:

- The occupational therapy workforce should clearly define their aims and objectives for all communities to understand.
- Training should be delivered from those who are delivering the best forms of occupational therapy and this must include families and ex service users.
- OTs working in hospital should be able to link the individuals into the community according to their needs.
- They should offer their services to Black businesses to help create an environment of wellbeing. This in turn would encourage people in those businesses to take on an individual from their own community and help to remove the stigma attached to mental illness.
- OTs should be concerned with humanity and environment in order to help people to live with themselves, and to live in their environment.
- They should look at housing choices, ensuring that the places where people are and will be living are environmentally sound, as this all impacts on wellbeing.
- OTs should be about intervention.
- Service users should evaluate OTs after they have used their services.
- The OT workforce should be reflective of the communities that they serve.
- The spiritual needs of the individuals should be addressed.
- Listen, Listen, Listen!

'*The ten-year plan should look at the way in which occupational therapy is named. It should bring on board other skills, which will be able to produce a service which is flexible enough to be constantly recruiting. For instance a*

*wellbeing agency that has on their books people like fitness instructors, personal development trainers i.e. partners which people will need in order to move on with their lives. Therefore the OT workforce should be able to see themselves as facilitators for people's mental health.'*

**Conclusion**

It is evident that occupational therapy in mental health has not worked well for Black and minority ethnic service users. The therapy offered has not been meaningful or purposeful in meeting their needs. It is evident that the area of community, what this means to the individual, and community development, need to be addressed on a more strategic level. This is of fundamental importance to the respondents and their wellbeing. The respondents felt that they would be better understood if the occupational therapy workforce was more representative of their community. It was also felt that the attitudes and preconceived ideas towards individuals need to be changed.

# Section 3 Results from Carers in Partnership, West Midlands

Date: 24th November 2005

The following is a report from a focus group discussion by members of the Carers in Partnership, West Midlands, on behalf of the Sainsbury Centre for Mental Health, as part of their work in developing a strategy for the College of Occupational Therapists. The text has been reproduced as submitted, apart from minor style changes.

Contact details: Carers in Partnership Care Services Improvement Partnership, West Midlands Development Centre, The Uffculme Centre, Queensbridge road, Mosely, Birmingham B13 8QY.

## Carers in Partnership, West Midlands

Carers in Partnership is a network of mental health carers, and their supporters, in the West Midlands region. The network is chaired and led by carers, and most of its members are carers. Its purpose is to ensure that carers are involved in the way that mental health services are planned, set up and run.

**Question 1. In your own view, how does 'occupation' impact on mental health and wellbeing?**
The carers believe that occupation makes a positive impact on mental health and wellbeing. The most important factor is that the occupation must be meaningful to the individuals and be of their own choice.

In the group's view, occupation, be it leisure, voluntary or paid work, domestic or hobbies, physical or mental activity:

- gives hope;
- promotes kudos and self-esteem;
- gives purpose to life;
- gives structure to the day;
- prevents deterioration in mental and physical state (particularly depression);
- promotes mixing socially and social inclusion;
- creates tiredness after a day's work to help sleep;
- lessens the time to be introspective;

Other thoughts included:

- suggestions given by professionals are found to be more helpful and motivating, therefore they are acted upon more often than suggestions from the family are;
- involvement by professionals is likely to include support for the individual;
- engagement in activities can involve a wider community;
- activities can be graded by occupational therapists;
- planning the day according to ability; need for rest, activity etc. is helpful.

**Question 2. What do occupational therapists do and how do they do it? What makes their work distinctive or unique, if at all, from that of other clinicians?**
In the carers' view, occupational therapists:

- are able to see and deal with a whole person approach;
- have an important 'hands on' role;
- are well educated with a practical focus;
- have a wide-ranging role;
- have good communication skills, and work well with others;
- are in a position to develop links with other agencies;

- have a flexible approach;
- are actively involved in social rehabilitation and inclusion;
- focus towards recovery and interdependence;
- look for uniqueness within the individual, developing old and new skills and education to meet these needs;
- help take pressure off the carer and family by providing rehabilitation to aid greater independence;
- as key workers, are effective and appreciated.

**Question 3. Occupational therapy in mental health exists as many levels (e.g. specialists and support workers, senior practitioners) and in several locations (e.g. assertive outreach, community and mental health teams etc.). Of the eight listed items, which one describes the core work that OT should do?**
The carers felt that no single item could be prioritised but that several were linked together as a priority:

- assessing occupational needs and functioning, with improving functional ability (as the latter follows assessment);
- increasing access to occupation, including employment and promoting social participation;
- promoting health and preventing disease together with preventing or alleviating disability;
- community development.

We were unsure what this means; carers would support occupational therapists in work that:

- reduces stigma;
- takes services into mainstream community centres;
- enables people to receive help without stigma, fitting their cultural background e.g. the mosque;
- enables the mentally ill to be readily accepted and not treated as second class citizens;
- enables people to accept the mentally ill living next door to them.

The group felt improving the 'quality of life' is a catch-all and subjective phrase. It should develop from an occupational therapist's assessment. The quality of life improvement is the aim that follows assessment and the steps, planned with the service user's co-operation.

**Question 4. Where does occupational therapy in mental health work (beyond the public sector)? Should the professional encourage and support this?**
The group was unaware of work in non-statutory services, other than legal claims and accident work.

The group felt strongly that occupational therapy should not work beyond the public centre; more of this therapy should be employed in mental health. The lack of occupational therapists results in them being spread too thinly.

Providing the focus is on promoting health and ability of the mentally ill, there is a role for this therapy in:

- voluntary organisations/charities working in mental health;
- education, colleges etc. working with the mentally ill;
- private clinics working with the mentally ill;
- work places working with the mentally ill;
- family work, where their role is most effective.

'*Their focus must be on the needs of the individual they have professional responsibility for.*'

**Question 5. Do you feel that (a) basic education and training in mental health and (b) continued professional development opportunities for occupational therapists is more appropriate? If not, how would you suggest it needs to change (e.g. training in Cognitive Behaviour Therapy or Solution Focused Brief Therapy, employment support?)**

**(a)**
As we understand it, the training of occupational therapists varies from college to college. Occupational therapists lack training in mental health. Clinical placements take up one third of the three-year B.Sc. courses. Some sorts of mental health problems or illness are said to affect one in four of the population. Therefore it seems important that mental health education/training should be part of all professional training and mental health included urgently in OT courses.

- All OT students should be exposed to placement with mental health service users and their families.
- A basic training of two or two and a half years with a year or six months in a mental health or specialty is recommended.
- Service users and carers are involved in the training of many professionals. Occupational therapists would benefit from this experience. Carers and service users could be employed as visiting lecturers.
- A postgraduate course/diploma in mental health would show the profession's/individual commitment to mental health/illness.
- More effort should be made to introduce young people to occupational therapy by better informed careers officers.

**(b)**

- Training in mental health needs to be comprehensive to include cognitive therapy and DVT and family work.
- Support for short courses should be made available.
- OT assistants should be given short courses,
- The portfolio (post qualification) should encourage mental health studies.

**Question 6. How diverse (e.g. in terms of gender, range of skills and capabilities, reflective of local population etc.) is the occupational therapy work force? Does the workforce need to be more diverse to deliver better services? If so, how should this change?**

It seems that occupational therapists are, in the main, white and middle-class and female. Whilst there are a few men and low ethnicity in the profession however, change has been occurring in the last few years. Some service users want a male occupational therapist and personal choice needs to be catered for. Pay is low compared to many professions. Employment terms, conditions and pay must improve.
Suggestions:

- better conditions and pay may recruit older applicants with life experience;
- consideration of part-time courses, particularly for older recruits;
- re-training courses;
- support for training of assistant grades to professional status;
- bursaries for training; particularly financial help to older adults or assistants wishing to undertake professional training;
- consideration of the barriers to management and to higher salaries for occupational therapists. Occupational therapists who remain working with service users should not be financially penalised;
- target ethnic/minority groups and cultural training;
- target schools, career conferences and employment agencies;
- the OT profession could do much to raise the status of the profession by publicity about the role of OTs today. The publicity should explain the diverse role and environments where occupational therapy takes place.

**Question 7. How visible is occupational therapy in the government's mental health agenda? How can it be made more visible?**

- Carers believe that the occupational therapist professional is not high in the government's agenda. We have seen other professions targeted in the media e.g. teachers' recruitment on T.V.
- Occupational therapists should be on forums and given the same profile/status as other professional groups and promoted via NIMHE and programme leads.
- When posts for occupational therapists are advertised but not filled, they ought to be left vacant – not filled by any other professions.
- New workers have been targeted to work in mental health with success, filling a useful and important role e.g. graduate workers. The occupational therapist lead in NIMHE should research the number of occupational therapists needed in mental health and ways of recruitment to the profession either in a full or assistant role and ways forward to meet the need.
- The lack of a power base for occupational therapists at management level possibly hinders development of the profession. The British Association of Occupational Therapists could itself do more e.g. by ensuring that occupational therapy is a national workforce programme.

**Question 8. Please share with us of other areas you feel we need to consider in the development of the ten-year mental health strategy for occupational therapy.**

The professional body should consider the following:

- more training for assistants and technicians in mental health and in the skills that are useful to service users and their families;
- support for OTs by a team of assistants trained in a lower level of professional education;
- proactive recruitment – publicity about the importance of OT in mental health, particularly in social functioning;
- involve carers and service users in publicity – they can describe the diversity of the help they receive from OT;
- promote the status of the worker through imaginative publicity in the media attractive to the young and ethnic groups;
- use OT to teach in other professionals' training to enlighten others about OT's changing roles;
- the British Association of Occupational Therapists, if it does not already do so, would be advised to appoint a full-time person allocated to recruitment, linking with careers officers, universities, women's' magazines etc.

**Conclusion**
In conclusion, of the consultation group comprising 11 carers, only three had experience of access to occupational therapy working in mental health. All three had positive experiences. The remaining eight felt that access to an occupational therapist would make a significant contribution to their circumstances.

Carers in Partnership are pleased to have had the opportunity to contribute to the role and future training of occupational therapists. We hope that our contribution is helpful and given time will result in more occupational therapists choosing mental health work as a career.

# Recovering Ordinary Lives

## The strategy for occupational therapy in mental health services 2007–2017

*Results from service user and carer focus groups*

College of Occupational Therapists

Download for BAOT members

**www.cot.org.uk**

**Tel: 020 7357 6480 Fax: 020 7450 2299**



College of Occupational Therapists