



# Occupational therapy and people with learning disabilities

*Findings from a research study*

Alison Lillywhite and David Haines

College of  
Occupational  
Therapists



Specialist Section  
People with  
learning disabilities

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# Foreword

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The timing of this report could not have been more opportune. The White Paper *Equity and excellence: liberating the NHS* (Department of Health 2010), published by the coalition Government, is proposing very significant changes in England in the way that health services are commissioned and treatment is provided. New proposals will also follow for the rest of the UK. As the above White Paper indicates, the challenges are perhaps at their greatest at the complex interface between health and social care and in the support of people with lifelong conditions who may also experience significant health inequalities, such as people with learning disabilities. The wider social context in the UK is the importance given to choice, inclusion, and participation, and on enabling people with learning disabilities to have more control over their own lives through individual budgets supported through the process of person-centred planning.

What is published in this report arises from a substantial programme of research that has used a variety of methodologies to look in depth at what it is that occupational therapists do, the standards that are expected, and the views of other stakeholders in services for people with learning disabilities. What emerges is a strong enthusiasm for, and commitment to, the field of learning disabilities; an identification of the particular skills that occupational therapists can bring to this field; and their role within the wider multidisciplinary team. The report emphasises the value of intense and often long term commitments to individuals with learning disability and the benefits that can arise whether it is in improved functional abilities, increasing independence, or in opportunities to engage in more meaningful employment. At this time of re-organisation and financial challenge, clarity as to our roles and expertise is essential as we all struggle with management structures and policy demands, whether from central government, the local authority or the provider NHS trust.

This report unequivocally advocates for occupational therapy but at the same time expresses concern as the evidence base is limited. The challenge for community inter-agency and multidisciplinary services, such as those for people with learning disabilities, is to develop the means whereby the case for the work that is done can be robustly made and supported, and services are also able to respond accordingly as the evidence becomes apparent indicating that changes may be required. It is this challenge that the adult theme of the NIHR Collaborations for Leadership in Applied Health Research and Care for Cambridgeshire and Peterborough is seeking to address.

There is also the challenge, particularly for occupational therapists, that has come with, for example, the use of new technologies. These have the potential to enhance independence and reduce risk but perhaps with a reduction in face-to-face contact. For these reasons, occupational therapists must have a vision that enables them to anticipate developments and to lead on such developments rather than follow policy demands. This comprehensive examination of the state of occupational therapy within learning disabilities provides the opportunity to reflect, not just on the here and now, but most importantly also on the future as new demands emerge, whether they are financially or policy driven. The changes over the last 20 years or more in services for people with learning disabilities have been astonishing, yet problems within services remain and official or informal enquires still identify health inequalities and the failings of services. However, at its heart this paper is very positive – it is certainly to be welcomed.

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# Executive summary

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Occupational therapists work with people to promote health, prevent disability and develop or maintain abilities (COT 2009). Those who work with adults with learning disabilities are often based within local community teams.

This research was commissioned by the College of Occupational Therapists and its Specialist Section – People with Learning Disabilities with the aim of exploring and documenting the nature of occupational therapy with people with learning disabilities across the United Kingdom, from the perspectives of occupational therapists and support workers.

Occupational therapists who work with people with learning disabilities were initially audited against current standards (OTPLD 2003) and discussed their practice in focus groups. Support workers of people with learning disabilities were also interviewed to gain their perspective.

## Summary of key findings

### **1 Occupational therapists have a unique role and perspective from their training**

They bring a unique understanding of the importance of engagement in occupation and are passionate about their person-centred and practical role, which focuses on independence and requires them to be adaptable, flexible and creative problem-solvers.

### **2 Occupational therapists assess the impact of learning disability on occupational performance**

Through direct observation of occupational performance in a real environment, a real understanding of strengths and needs is gained. This allows occupational therapists to be very specific about what someone can and cannot do and the type of support they need. A wide variety of assessment tools, some standardised, are used.

### **3 Occupational therapists work intensively over a long period of time with people with learning disabilities**

The importance of intensive or long-term work due to this being a lifelong condition where needs change, was an important aspect of the occupational therapist's contribution. Occupational therapists contribute to the meeting of wider social policy priorities of promoting rights and supporting independence, control and inclusion. This may include direct skills development work. Sometimes work with people with complex needs, including those with profound and multiple learning disabilities and those whose behaviour may be found to be challenging is prioritised.

### **4 Occupational therapists work with others to meet the needs of people with learning disabilities**

This includes family members, support workers, other multidisciplinary team members as well as those in mainstream health and social care services, for example other

occupational therapy services. The occupational therapy role is often a consultative one, making recommendations for support workers and families to carry out. A number of factors are identified that influence whether or not such recommendations are carried out.

## **5 Outcomes of occupational therapy with people with learning disabilities**

Outcomes are dependent on good working relationships although these can be difficult to measure.

## **6 Recognition of the occupational therapy role**

Occupational therapists recognise the importance of evidence-based practice and are keen to increase the evidence base for their practice, though time and resources often limit this. They need to be assertive in promoting a defined occupational therapy role and ensuring that this is acknowledged and recognised in key national documents.

## **7 Wider health and social care policy impacts on occupational therapy with people with learning disabilities**

Occupational therapists support the rights of people with learning disabilities to access mainstream health and social care, by concentrating on those needs that relate to their learning disabilities and promoting inclusion into mainstream occupational therapy services for other needs. By working in partnership and in a consultative role they ensure that an individual gets the benefit of both areas of expertise.

The current financial climate impacts both on the resources available for support packages and on the number of occupational therapists in post. Policy changes related to eligibility and waiting list targets create a focus on *quantity* of referrals rather than *quality* of service and make long-term occupational therapy difficult, encouraging a crisis response rather than preventative work.

## **8 Developing the necessary skills to work with people with learning disabilities**

Wherever they work, *all* occupational therapists need knowledge and skills to be able to work with people with learning disabilities. Specific content and increased student practice placements in learning disabilities are therefore required in pre-registration occupational therapy courses. After qualifying, little *specific* post-registration training is available (and the resources to fund such training are variable), but occupational therapists keep up to date through networking.

## **Recommendations**

Within the conclusion of the report recommendations are made for occupational therapists working in specialist learning disability teams and their managers. There are also recommendations for those involved in occupational therapy education, the College of Occupational Therapists and the College of Occupational Therapists Specialist Section – People with Learning Disabilities and those involved in occupational therapy research.

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# 1 Introduction

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Occupational therapists work with people to promote health, prevent disability and develop or maintain abilities (COT 2009). The main aim of occupational therapy is to maintain, restore, or create a beneficial match between an individual's abilities, the demands of their occupations and the demands of the environment, in order to maintain or improve their functional status and access to opportunities for participation (COT 2003a). This can involve helping someone learn new ways of doing activities, adapting equipment or materials used every day and making changes to the places where they live and work.

Occupational therapists work with people with learning disabilities, both within services accessed by the wider population and within specialist teams; they have wide roles supporting engagement in occupation and promoting independence and community participation (OTPLD 2003). They describe doing valuable work to enhance the quality of life of people with learning disabilities, though there has been a paucity of research evidence documenting this practice (Parry and Jones 2008).

## 1.1 Context

Since 2000, each of the four countries of the United Kingdom has developed policies or visions of how the needs of people with learning disabilities should be met. Occupational therapy is provided within the context of these policies. Although the emphasis and the language used may vary slightly in each country, the overall direction across the United Kingdom is remarkably similar. This can be seen in the following description of aspects of policy that seem particularly relevant to occupational therapy.

In **Scotland**, *The same as you?* (Scottish Executive 2000) describes a commitment to improving the quality of life for people with disabilities and reflects wider policies including social inclusion, equality and fairness and the opportunity for continuous learning. It seeks to enable people with learning disabilities to lead 'normal' lives and to:

- be included in community life, education, leisure and recreation, day opportunities and (in particular) employment;
- be better understood and supported by the communities in which they live;
- have information about their needs and the services available;
- be at the centre of decision making with more control over their care;
- have the same opportunities as others to get a job, develop as individuals, spend time with family and friends, have their own home and enjoy life (with any extra support they need to do this); and
- be able to use local mainstream services wherever possible and rely on specialist services only when they need them.

In **Northern Ireland**, *Equal lives* (DHSSPSNI 2005) presents a range of proposals for improving the lives of people with a learning disability and their families based on five key values:

- Citizenship – as individuals first and foremost, people have the right to be treated as equal citizens.
- Social inclusion – as valued citizens, people should be enabled to use mainstream services and to be fully included in the life of the community.
- Empowerment – people should be enabled to participate actively in decisions affecting their lives.
- Working together – conditions must be created where people with a learning disability, families and organisations work well together in order to meet needs and aspirations.
- Individual support – supporting people in ways that take account of their individual needs and help them to be as independent as possible.

In **Wales**, *Fulfilling the promises* (National Assembly for Wales Learning Disability Advisory Group 2001) led to a statement on policy and practice (Welsh Assembly Government 2007). This is based on the principle that all people with a learning disability are full citizens, equal in status and value to other citizens of the same age and with the same rights to:

- live healthy, productive and independent lives with appropriate and responsive treatment and support to develop their maximum potential;
- be individuals and decide everyday issues and life-defining matters for themselves, with appropriate advice and support to join in all decision making which affects their lives;
- live their lives within their community, maintaining the social and family ties and connections which are important to them;
- have the support of their communities and access to general and specialist services that are responsive to their individual needs, circumstances and preferences.

In **England**, the original *Valuing people* White Paper (Department of Health 2001) was recently reviewed and updated in *Valuing people now* (Department of Health 2009a). With a particular focus on including *all* people with learning disabilities, on personalisation of services, citizenship and 'having a life' (including addressing needs related to health, housing, work, education and relationships), it is underpinned by the following four core values:

- Rights – people with learning disabilities and their families having the same human rights as everyone else.
- Independent living – meaning not necessarily living or having to do everything alone, but having greater choice and control over the support needed to go about daily life; and improved access to housing, education, employment, leisure and transport opportunities and to family and community participation.
- Control – being involved in and having control of decisions, with the information and support needed to understand different options, their implications and consequences.
- Inclusion – having the support to be able to participate in all the aspects of the community, for example to work, learn, be part of social networks and access services.

In November 2003, the College of Occupational Therapists, with its Specialist Section – People with Learning Disabilities (then known as OTPLD) published a set of Principles for Education and Practice for occupational therapists working with adults with learning disabilities (OTPLD 2003). These principles are set out in the box below, and reflected the core values outlined in those government policy documents that had been published. The aim was to establish a recognised set of standards in order that occupational therapists might provide a uniform quality of service to all people with learning disabilities.

**Principles for education and practice in occupational therapy with people with learning disabilities (from OTPLD 2003)**

1. Occupational therapists working in learning disability services provide a service for people whose primary reason for referral relates to the effect of their learning disability upon their occupational performance.
2. People with learning disabilities need to be enabled to have choice and influence over their occupational therapy intervention.
3. People with learning disabilities have the right to access generic health and social care.
4. Occupational therapy services should be provided in partnership with the person with learning disabilities, his or her carers and all relevant agencies.

## 1.2 Research aim

This research was commissioned and partially funded by the College of Occupational Therapists and its Specialist Section – People with Learning Disabilities. Its intention was to record occupational therapy practice and consider its impact on the lives of people with learning disabilities and the aim is therefore:

*To explore and document the nature of occupational therapy with people with learning disabilities across all four countries of the United Kingdom, from the perspectives of occupational therapists and those paid to support people with learning disabilities.*

This report, in describing the process and findings of the research, aims to provide a rich and detailed description of occupational therapy with people with learning disabilities in the United Kingdom. As well as its relevance to occupational therapists, it is hoped that it will be of use to others working with people with learning disabilities, to commissioners of services and of course to people with learning disabilities themselves and their families.

## 1.3 Definitions of terms used in this report

### 1.3.1 Learning disabilities

Government policy documents in England and Northern Ireland use the definition of the term 'learning disabilities' from *Valuing people* (Department of Health 2001). As the definitions in Scotland and Wales are similar, that same definition is used in this research and the term can therefore be taken to mean the presence of:

- a significantly reduced ability to understand new or complex information and to learn new skills; with
  - a reduced ability to cope independently;
- which started before adulthood and had a lasting effect on development.

### **1.3.2 Support worker**

The term 'support worker' is defined as someone who:

- is paid to provide direct support to people with learning disabilities; and
- assists them to carry out their daily tasks (Mencap 2009).

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# 2 Methods

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The research was carried out in three consecutive phases and received ethical approval from the College of Occupational Therapists and the NHS National Research Ethics Service.

The **first phase** aimed to explore current practice in relation to established standards. An audit of the extent to which occupational therapists working with people with learning disabilities across the United Kingdom are meeting the standards of practice described in OTPLD (2003), was carried out using a questionnaire.

Having established in what ways standards of practice were being met, the **second phase** aimed to explore the nature of occupational therapy with people with learning disabilities today and to identify examples of good (and new) practice. The views of occupational therapists working with adults with learning disabilities were sought using eight separate focus groups across the United Kingdom.

The **third phase** aimed to explore occupational therapy with people with learning disabilities from the perspective of key stakeholders. The important role of the occupational therapist as a consultant, making recommendations for others such as support workers to follow, is evident in the literature (see for example Donati 2009) and was immediately apparent during phase 2 of the study. This final phase therefore sought the views of support workers, as an example of a key stakeholder group in occupational therapy with people with learning disabilities.

The methods used to gather and analyse the data in the three phases of this research are described in full in Appendix 1.

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# 3 Research findings

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The findings from analysis of the data from the questionnaire, focus groups and telephone interviews are discussed under eight predominant themes. All quotations are from occupational therapists participating in the focus groups in phase 2 of this study, except where otherwise indicated.

## 3.1 A unique role and perspective

Occupational therapists are passionate about their unique role working with people with learning disabilities. Their ability to work holistically, practically and creatively, is possible due to the particular perspective that they bring to their multidisciplinary teams from the core skills and philosophy of their training.

### 3.1.1 It's a passion

Occupational therapists talk passionately about working with people with learning disabilities. Many work in the field for a long time with 73 per cent of questionnaire respondents having six or more years, 54 per cent 11 or more years and 30 per cent 16 or more years' experience (see Table 1 in Appendix 2). Although those who perceive themselves to have more experience may be more likely to participate in a research study such as this, it does indicate the strong commitment of occupational therapists in this area:

*"once in learning disabilities you stay – a job for life".*

For one focus group participant, the complexity of the job was what was exciting about it while another enjoyed the fact that there is no set protocol or pathway and that no two people with learning disabilities are the same. Another liked the fact that the variety of the job and its broad range of complexity meant that she was always learning:

*"I love sometimes feeling out of my depth – it stretches me."*

Generally occupational therapists like the fact that their jobs vary every day giving them the chance to:

*"think on your feet".*

As mentioned above, they feel they are practising real occupational therapy and also that they can use their personal skills and instincts. They give a sense of real commitment to making change for this group of people and value the fact that there is:

*"time to develop a relationship – you are part of their life for a while and get to know them over years".*

When discussing how they have come to be working as occupational therapists with people with learning disabilities, many refer to previous experience prior to training, for example as support workers, or as students or on a newly qualified rotational post.

Some highlighted that working with people with learning disabilities does not suit everyone because of the less structured approach and lack of a set pathway. One focus group participant thought it would be a difficult area to work in if the passion was absent:

*“You can tell when an applicant is not going to be right – it isn’t second nature to everyone.”*

### **3.1.2 A full training**

Occupational therapy training uniquely covers both health and social care with an emphasis on both physical and mental health. This enables occupational therapists to bring specific knowledge and a different perspective to other members of the multidisciplinary team. It seems particularly important when working with people with learning disabilities, where a really good understanding of the impact of complex needs on wellbeing is required:

*“In learning disabilities occupational therapy, you literally call on every part of your training.”*

Occupational therapists describe clear roles within their multidisciplinary teams and like the fact that on a daily basis they utilise their core occupational therapy skills and every component of their training. They emphasise the importance of utilising their core skills of observation and problem-solving and value the fact that:

*“In learning disabilities you really get to home in on the core things taught – proper occupational therapy.”*

Improvements in medical care now mean that people with learning disabilities live longer (NICE and SCIE 2006) and occupational therapists feel that their broad knowledge means that they are well placed to address changing physical and mental health needs through their later life.

Consistently, occupational therapists describe their practice as holistic, supporting this assertion, by referring to the range of needs someone with a learning disability might experience and how this necessitates a broad range of skills:

*“an amazingly big jigsaw puzzle”.*

They describe how, often through long visits and remaining involved with people over a long period of time, they strive to really understand the whole person. The breadth of occupational therapy training seems key to allowing occupational therapists to practise in this particularly holistic way.

### **3.1.3 A focus on occupation and enabling independence**

Occupational therapists consistently describe their focus on maximising the independence of people with learning disabilities with one participant commenting that people would be more dependent without this. Their assessments:

*“get under the diagnosis in order to facilitate them being as independent as possible . . . in whatever they want to do”.*

There appears to be a growing role for occupational therapists with the trend towards supported living, where people live in their own homes with individually tailored support, rather than in residential care. The range of possible inputs is illustrated using examples such as supporting someone to develop their skills in independent travel, looking after their home, accessing local leisure facilities and shopping.

When discussing independence, occupational therapists seem to refer to this concept in its wider Social Model of Disability sense (Oliver 1996) rather than its narrower everyday sense of being self-supporting. Their focus is on ensuring that someone has the right amount and type of support to achieve a maximal level of independence and may include working with others around someone needing more support:

*“through functional assessment, we also help to advocate when they do need some support or care”.*

This is seen as an example of adapting the social environment to meet an individual's needs and enabling the person to make the best use of their skills.

### **A key focus on occupation**

When occupational therapists are asked what they see as unique in their roles, a consistent response is that they focus on the occupations of people with learning disabilities and daily activities. They refer to the quality of someone's life, to the importance of them participating in a range of meaningful activities and to engagement and fulfilment, identity and self-efficacy. Their core philosophy is that engaging in valued and meaningful activities is paramount to people's health and wellbeing.

This focus on and understanding of occupation is regarded by occupational therapists as a unique feature which they bring to their multidisciplinary teams:

*“We are the only profession that assesses occupational performance, that uses occupation as a means of assessment and treatment (occupation is our therapy).”*

In particular they feel that no other team members assess occupational performance in the same way (see further about this in section 3.2) and that others make sense of occupation differently and do not have it as their key focus.

### **Meaningful occupation rather than occupational deprivation**

Occupational therapists emphasise the importance of engaging in valued and meaningful activity to promote the physical and mental health and the general wellbeing of people with learning disabilities:

*“You are actually out with them trying to access the local leisure centre or things that make life meaningful – can they get to local shops, use the library, interact with people there? Start looking at meaningful occupation.”*

The quality of an individual's occupational life is important to their sense of identity and self-esteem and this natural concern of occupational therapy supports key priorities in

government documents (such as by the Department of Health 2009a and the Welsh Assembly Government 2007):

*“They talk about meaningful activity, daily routines and the environment – all things occupational therapists do.”*

Focusing on what someone actually spends their time doing, occupational therapists often work with people whose lives are lacking in meaningful occupation and who are ‘occupationally deprived’ as defined by Wilcock (2006). An understanding of the impact of this, and an imbalanced occupational life is important when considering why someone might behave in a challenging way (see further section 3.3.5).

### **Supporting others to have an occupational focus**

The consultative role that occupational therapists have with those who support people with learning disabilities on a day-to-day basis will be discussed in detail in section 3.4. This role includes ensuring that others recognise the value and importance of occupation and that this is reflected in individuals’ care plans. Occupational therapists seek to ensure that people are enabled to engage and participate in activity that is meaningful to them:

*“not just existing but enjoying life” rather than “sitting on their backside all day at Day Services doing nothing”.*

Occupational therapists recognise that some support staff are very good at enabling people to engage in meaningful occupation, but do refer to institutional practice in, for example, some residential settings with some teams not recognising limitations to an individual’s quality of life:

*“For some, a good day is people [being] clean and fed, sitting quietly (maybe chewing fingers but as long as they’re quiet).”*

The importance of going into a residential or day service and *questioning* how someone spends their day is emphasised, as lack of meaningful occupation can be an example of negligence. Occupational therapists have an important role in picking up on restrictive practices, for example questioning why the door to the kitchen might be locked or why someone does not have access to the fridge in their home.

### **3.1.4 Practical, adaptable and persistent – creativity in moving things forward**

Occupational therapists describe how they work in practical ways and are adaptable and flexible in solving problems.

#### **Practical**

Occupational therapists feel they have particularly practical roles within their multidisciplinary teams. They see themselves as activists with a hands-on and pragmatic way of working, trying a wide variety of strategies to engage people and work in a creative way:

*“[You] roll up your sleeves and get your hands dirty.”*

Actually doing activities with people with learning disabilities and, for example, assessing their functioning through direct observation of them (with their consent) is a distinctive aspect of their practice. This is discussed further in section 3.2.1.

### **Adaptable and creative**

People with learning disabilities have extremely varied abilities and needs, and they therefore require varied and individualised occupational therapy interventions:

*“People talk about working in learning disabilities as if it was one thing.”*

*“What’s needed to make a bus journey varies hugely from person to person.”*

The wide range of needs and ways to become involved means that occupational therapists must be adaptable and flexible when working with each individual. They see it as part of their training to work out how to find ways around problems and to be creative:

*“being a bit innovative with each person – doing something you haven’t done before”.*

Occupational therapists describe bringing personal skills, from life experience as well as their training, to their work, for example their therapeutic use of self. Their creativity contributes to their ability to work in person-centred ways to meet individual needs (discussed further in section 3.1.7 below).<sup>1</sup> Occupational therapists feel that they are particularly skilled at this, in part because of their knowledge of activity analysis (see section 3.1.5 below).

A useful example to illustrate this was given by one focus group participant who described receiving last-resort referrals for individuals who lack motivation and who are in need of some form of meaningful occupation. In such situations, the specialist need is for someone to be creative, to:

*“look at it in a different way and not write the person off”.*

### **Persevering and moving things forward**

Occupational therapists describe persevering and trying different routes around barriers even when this takes a long time. They feel that this problem-solving aspect of their role with people with learning disabilities really helps the person to move forward. This unique perspective enables them:

*“to see things that others don’t see”, when things are “stuck in a rut”.*

One participant highlighted how the occupational therapy assessment can help unite people with different issues as it can act as a bridge between different parties (for example the person themselves, their family and support workers):

*“It’s my report and recommendations that draw needs and idealistic goals into a realistic plan.”*

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<sup>1</sup> The need for professionals to find creative responses and solutions to the behaviour of people with learning disabilities that others find challenging is specifically promoted in *Challenging behaviour: a unified approach* (Royal College of Psychiatrists et al 2007).

### 3.1.5 Underpinning theory

Underpinning occupational therapy theory supports work with people with learning disabilities. Occupational therapists describe their practice models and ability to analyse activity as being particularly important to their practice.

#### Occupational therapy models

Some occupational therapists emphasise the value of their profession's practice 'models' in helping them to understand the complexities of people's lives. They describe the Model of Human Occupation (MOHO) (Kielhofner 2007) and the Canadian Model of Occupational Performance (CAOT 1997) as providing different means of identifying and conceptualising an individual's strengths or difficulties. They feel this enables them to question and analyse information from their assessments (see also section 3.2 below) and to reach a deeper understanding:

*"[The MOHO] is particularly fitting for [people with] learning disabilities, because of all the different factors, environment and volition, motivation choice, control."*

Occupational therapy models such as these complement those used by other members of multidisciplinary teams. One focus group participant particularly valued the alternative perspective they provide to the behavioural models, such as Applied Behaviour Analysis (Cooper et al 2007), used by many others in her team.

#### Activity analysis

Occupational therapists use their core skill of activity analysis to enable them to adapt activity to an individual's needs and then to grade the activity to build independence in small steps. They feel that having this tool supports their ability to problem solve and:

*"dissect what is getting in the way of someone being able to do what they really want to do".*

They suggest this is particularly valuable when working with people with learning disabilities and that breaking down activity using this technique is not the key focus of any other profession. Others may do some analysis of activity, but not, occupational therapists feel, in the same way or to the same depth.

### 3.1.6 The environment

Occupational therapists describe how use of the practice models of their profession (mentioned above) supports understanding of the physical, social, organisational and cultural environments in which people with learning disabilities live their lives. This is a particular focus that allows them to identify the environmental factors that get in the way of the person doing what they want or need to do.

The **social, organisational and cultural environment** includes the quality and type of support someone receives. This is an important influence on that person's occupational performance and participation that will be explored in section 3.4.2.

The **physical environment** includes all the spaces that someone spends time in and occupational therapists describe their particular emphasis on working across these environments. The importance of assessment and ongoing work with people in 'real'

environments is described in section 3.2.1. The sensory aspects of the environment are particularly emphasised by some occupational therapists:

*“As occupational therapists, we’ll see the environment and what affect it may have on the person emotionally . . . too much in this room or there’s not enough in this room . . . it’s too bright . . . echoey.”*

*“In sensory processing terms, the environment is crucial to people on the autistic spectrum.”*

Needs identified following assessment of the physical environment are sometimes met, in whole or in part, through the provision of equipment and adaptation of buildings. How the role of occupational therapists in learning disability teams fits with that of their colleagues in generic social care teams is the subject of much debate and will be explored in section 3.7.3 below.

### **3.1.7 A person-centred focus on what interests and motivates people**

Person-centred practice is key to learning disability policy across the United Kingdom (e.g. Department of Health 2009a, Scottish Executive 2000, DHSSPSNI 2005) and to the government’s agenda regarding personalisation of health and social care (Department of Health 2006).

Working in a person-centred way, supporting people to make informed decisions and enabling them to set their own goals is central to occupational therapy practice and these are well-established values of the profession. Along with occupational therapists’ ability to motivate people, this underpins their participation in Person-Centred Planning with individuals. However, they emphasise the importance of having time to develop relationships with people to be able to work in a person-centred way.

Occupational therapists illustrate this person-centred way of working with examples of how they:

- *“start with the person and work out from there”;*
- assess people in their own environments rather than expecting them to come into a clinic for assessment;
- carry out a bathing assessment very early in the morning as this is the natural time the activity would take place;
- are adaptable and flexible;
- individualise their approach to each person taking the time to get into an individual’s world;
- find out what is important to the person rather than what is important to others;
- work with someone at their own pace.

#### **Motivation to participate in activity**

Occupational therapists often concern themselves with what motivates someone to participate in their occupations and a key reason for being involved with someone is when their motivation to engage in activities is reduced. They describe how the concept of ‘volition’ from the MOHO (Kielhofner 2007) supports them in considering the values, interests and beliefs people with learning disabilities have about their self-efficacy and personal capacity:

*“We have skills to help motivate somebody, find something they’re interested in.”*

They work with people who are occupationally deprived or who others are struggling to find a way to engage in activities. Occupational therapists feel that they have a particular ability to engage people who have not usually accessed services and that they look at engagement and participation in a unique way. The real understanding of someone that they gain through assessing strengths, needs and interests (see section 3.2.1 below) means they can provide realistic and meaningful options for activities that *do* motivate that person. Sometimes the whole system surrounding an individual needs motivating – including support workers and other team members (see section 3.4).

Occupational therapists negotiate small achievable goals with people to increase their motivation and improve their quality of life. Whatever the complex needs of the individual (for example they may be on the autistic spectrum, have profound and multiple learning disabilities, a dual mental health diagnosis or a sensory integrative dysfunction) a focus on re-motivation and occupational engagement is important (de las Heras 2003).

### **Communication**

Occupational therapists emphasise the importance of individualising communication to the needs of each person and the need to be creative and flexible in the methods they use, especially with those who do not communicate verbally. They describe, for example, ensuring that information is accessible by adapting appointment letters, group timetables, recipes and instructions, by simplifying language and using pictures and symbols. They often work closely with speech and language therapists to support this.

Along with other members of their teams, occupational therapists have a role in advising others, such as mainstream occupational therapy services, about the communication needs of the people they are working with as they may otherwise communicate using language that is too complex. They often work jointly to facilitate access to such services (see section 3.4.3 below).

### **Making choices**

People with learning disabilities are often very reliant on others (for example support workers) to make assumptions about their needs. If a good communication strategy is not in place people can fail to understand what someone wants and/or is trying to communicate. Occupational therapists stress the importance of complying with the *Mental Capacity Act 2005* (Great Britain. Parliament 2005) and enabling people to make choices, empowering them to make informed decisions and to set their own goals to improve their quality of life.

Making a meaningful and purposeful choice may mean that someone needs a lot of support to identify options that motivate them and that they can then try out:

*“How can you expect someone to choose when they haven’t experienced anything different?”*

Sometimes the choices available to people are limited by finances, or the amount of support they are funded to receive and this impacts on how person centred services can be.

### **Advocacy and person-centred planning**

An important aspect of being person centred is a co-ordinated approach through 'Person Centred Planning' and commissioning (as envisaged in Department of Health 2009a, Welsh Assembly Government 2007 and DHSSPSNI 2005), or 'Personal Life Planning' (as described in Scottish Executive 2003). Occupational therapists describe their key role within this, with their focus on meaningful and purposeful activity and promotion of choice.

Although person-centred planning seems more established in some localities than others, responses to the questionnaire indicated that approximately two-thirds of occupational therapists are involved in the person-centred plans of those they work with. This varies from attendance at planning meetings as required, to being the co-ordinator of an individual's plan – though taking on this role is often difficult due to the long-term commitment required.

Occupational therapists perceive advocacy as a central component of their work. This includes advocating for someone when their assessment indicates that they require more support or lobbying local facilities (for example a swimming pool, about access to their premises). It extends to ensuring that mainstream health services (e.g. GP surgeries and acute hospitals) understand the needs of people with learning disabilities and working with policy makers to ensure learning disability services are developed around what people need rather than expecting people to fit within existing services.

## **3.2 Assessing the impact of learning disability on occupational performance**

Across all eight of the groups, occupational therapists discussed assessment of people with learning disabilities. The general purpose of this broad role in assessing needs is to ascertain the impact of someone's learning disability on their occupational performance (i.e. how it affects their life and their engagement in the occupations that are important to them). This assessment of quality of occupational performance is described as particularly important with people with learning disabilities, who do not always know, or are not always able to verbalise their skills and needs. Responses to the questionnaire suggest that 73 per cent of referrals to occupational therapists in community learning disability teams involve these skills assessments (see Table 2 in Appendix 2).

### **3.2.1 Real understanding from a unique way of assessing**

This core role in assessing function is an area of expertise that occupational therapists feel they uniquely bring to their multidisciplinary teams and to people with learning disabilities. They describe how they assess in a different way to other members of their teams and attach importance to their assessments being objective, to questioning things and not getting all their information from one source. Much assessment is through direct observation:

*"We don't just ask questions . . . actually observing picks up what they can and cannot do."*

Assessments are made as meaningful as possible, by carrying them out in a real environment, such as the environment where the person will carry out the relevant activity. Examples of the range of settings in which parts of assessments might be carried out include the individual's home, day service, college, or workplace and relevant settings within their local community, such as a leisure centre or supermarket.

Occupational therapists sometimes ask similar questions to their colleagues, but have a different occupational perspective. Using their occupational therapy practice models, they analyse complex clinical situations in order to understand how the information from their assessments gives them a better understanding of the whole person and their individual needs:

*"The realism we can supply by accurately assessing what the person can and can't do and the risks around it."*

The detail of occupational therapy assessments of the quality of occupational performance leads to a real understanding of individuals' strengths and needs:

*"We really strive to understand the detail of exactly how this person lives their life."*

*"We can really pinpoint what someone's skills are and where their shortfalls are."*

The real understanding provided by occupational therapy assessments therefore plays an important role in meeting these requirements and ensuring that people get support that works for them.<sup>2</sup>

### 3.2.2 Objective assessment of support needs

Occupational therapists receive increasing numbers of referrals for assessment to pinpoint people's strengths and identify their support needs; information from these assessments is then used by other disciplines to evidence the need for and design of support packages. The assessments are relied upon by other team members and used to justify risk management and funding decisions. Occupational therapists are therefore an important part of the team decision to ensure that an individual gets the right support to meet their needs.

#### An independent and objective assessment

Occupational therapists stress how assessing people with learning disabilities by observing them doing things in natural environments increases validity as it adds important objectivity to assessments that might otherwise be based on speaking to family and support workers:

*"What makes us different is that we don't just ask questions . . . [other] assessment[s] may cover much of the same information as us, but we might then go on and do it WITH the person."*

Support workers seem particularly to value the independence of occupational therapy input:

<sup>2</sup> A recent publication on person-centred commissioning (CSIP 2009) places understanding the person as the essential starting point for designing, developing and purchasing support and services. A joint review of commissioning of services and support for people with learning disabilities and complex needs (CSCI/HC/MHAC 2009), specifically states that commissioning requires knowing what services people need to live a good life.

*"I thought it was very beneficial, because . . . it was a proper and honest assessment. . . . She seemed very understanding of the situation and she wrote . . . a report reflecting [the person's] holistic needs." (Support worker)*

However, it appears, that some occupational therapists find this position challenging to maintain. One focus group participant described being placed under pressure to change recommendations in her report due to the implications of funding them.

### **Advocating for the right support package**

Thorough assessment allows an occupational therapist to be very specific about support needs. Recommendations about meeting these needs may relate to both the amount and the type of support needed, including advice on how to approach the person, how to prompt and cue, or set up the environment and, in other words:

*"how hands on to be".*

These recommendations may, for example, allow a supported job or a residential placement to succeed by ensuring a better fit with the person. Additionally they may ensure that someone is supported in a more enabling way, thus promoting their independence.

Sometimes this may involve advocating for what is important to the person, or that they need more or different support to that they are currently getting. Occupational therapists feel that the distance from the funding decisions made enables them to advocate with fewer restrictions than their social work or care management colleagues and emphasise their ability to provide independent assessments focusing on what individuals need:

*"We haven't got an agenda so that helps the money go to the right place."*

In the focus group discussions, one participant stressed the importance of resisting the pressure to only meet 'substantial needs' (Department of Health 2003), though another recognised that where sufficient funding is not agreed to pay for the ideal care package, it is important to revisit this and find the best alternative within the limitations imposed.

### **3.2.3 Use of standardised and non-standardised assessments**

In order to gain the real understanding of people with learning disabilities referred to above, occupational therapists use a wide range of assessments and tools, including some standardised assessments. One of the principles in OTPLD (2003) is that standardised assessments should be used whenever possible and occupational therapists feel that they improve the quality of the information they can provide as well as having the advantage of measuring progress.

The findings indicate that the main standardised assessments used by occupational therapists with people with learning disabilities are:

- the Assessment of Motor and Process Skills (AMPS) (Fisher 2005) which is discussed further below;
- the Canadian Occupational Performance Measure (COPM) (Law et al 1994); and

- certain assessments from the Model of Human Occupation (MOHO) (Kielhofner 2007), including the Model of Human Occupation Screening Tool (MOHOST)(Parkinson et al 2006), the Volitional Questionnaire (de las Heras et al 2007), the Occupational Self Assessment (OSA) (Baron et al 2006) and the Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS) (Forsyth et al 2005). For one focus group participant, the value in using these assessments was to draw on the language of MOHO in her practice;
- The Pool Activity Level Instrument for Occupational Profiling (Pool 2007).

Occupational therapists often undertake post-registration training in sensory integration and this enables them to use standardised assessments from within that theoretical framework such as The Sensory Integration Inventory – Revised for Individuals with Developmental Disabilities (Reisman and Hanschu 1992) (see also section 3.3.4 below).

Some describe preferring to receive referrals for a specific need rather than to complete a particular assessment, such as the AMPS. They can then use their clinical judgement to choose the appropriate means of assessment for the person referred.

### **Assessment of motor and process skills**

The Assessment of Motor and Process Skills (AMPS) (Fisher 2005) is the standardised assessment that is most used by occupational therapists with people with learning disabilities and was the subject of much discussion within the focus groups. It requires observation of an individual performing two or three daily living tasks from the selection available within the manual. Certain tasks seem particularly to lend themselves to being used when assessing people with learning disabilities. These tend to be those that may be easiest to complete in the required standardised format (for example more basic personal care, food preparation and domestic tasks).

Those occupational therapists that regularly use this assessment speak strongly in support of it, and find it useful in highlighting people's occupational performance strengths and difficulties:

*"A helpful, useful tool – I'd recommend it to anyone."*

*"It does show you what they need or struggle with."*

Although one participant felt that the assessment could be "harsh", generally it seems accepted that the AMPS can be useful in pinpointing exactly where someone's difficulties are (for example if it is challenging to see what it is that is causing someone to struggle with their activities of daily living):

*"Actually it is helping you because it shows they will have difficulties because they won't understand and will still muddle along or that they struggle not to ask for assistance."*

The main debate about the value of this assessment is the difficulty of ensuring that the person being assessed understands exactly how they are expected to perform the task and that the assessment is therefore valid (see the next section about adapting the AMPS).

Occupational therapists stress that they do not use the AMPS as a 'stand-alone' assessment and that additional assessment is also likely to be needed. They also describe needing to use their clinical reasoning to *interpret* the results:

*"It is our ability to understand and interpret in view of the person we know that makes AMPS such a useful tool."*

Some community learning disability teams use the AMPS as part of their team eligibility assessment, to contribute to an assessment of whether or not someone has a learning disability.<sup>3</sup>

### **Tailoring occupational therapy assessment to meet individual needs**

Generally, occupational therapists indicate a wish to use standardised assessments with people with learning disabilities whenever possible (as suggested in OTPLD 2003). Responses to the questionnaire indicate that they are used for at least part of an individual's occupational therapy assessment in about 29 per cent of referrals (see Table 3 in Appendix 2), though this makes it apparent that occupational therapists do not always find it possible to use them. Overall there seems to be a recognition that they are:

*"very useful, but only for some people – not the be all and end all"*

and that:

*"There isn't a perfect standardised assessment."*

Some find it difficult, within the existing occupational therapy assessments available, to identify tools that cover the wide range of abilities of people with learning disabilities. This is particularly the case when working alongside people with profound and multiple learning disabilities, for whom assessments such as the MOHOST may not discriminate sufficiently to measure change. While standardised learning disabilities assessments and standardised occupational therapy assessments exist, there is a need for development of specific learning disability occupational therapy assessments.

Some find that they have needed to adapt some of the standardised assessments (e.g. the AMPS and the OSA) and use them in a non-standardised way in order for them to be more accessible and applicable to people with learning disabilities:

*"You can't just get a standardised package off the shelf and use it – you always tweak it for the person."*

There is some uncertainty about whether minor changes affect the standardisation of the assessment. When using the AMPS, for example, it seems generally accepted that people with learning disabilities can practise tasks in advance in order to ensure that they are familiar and the expectations are understood. Some occupational therapists utilise pictorial AMPS task descriptions to assist with this.

Occupational therapists describe developing and sharing tools designed to be more accessible to people with learning disabilities. Examples include activities of daily living or interests checklists, with visual cues such as photos or symbols to aid understanding. There is a need to get these home-grown (or home-adapted) assessments standardised:

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<sup>3</sup> It is specifically recommended that use of the AMPS is considered for a person with a learning disability newly diagnosed with dementia (Royal College of Psychiatrists and British Psychological Society 2009; NICE/ SCIE 2006).

*“We are not very good at getting our tools standardised – we need to . . . work towards getting home grown assessments shaped and standardised.”*

### 3.2.4 Increasing demand for assessment and less direct intervention

Occupational therapists describe receiving increasing numbers of referrals specifically requesting assessment, but which do not necessarily lead to ongoing treatment or intervention:

*“The amount of referrals from care management has gone off the scale – regarding how much support does the person need?”*

Some express concerns that they are almost routinely receiving referrals from their colleagues when an individual is moving accommodation or their support needs are being reviewed, particularly in integrated health and social care teams. Many referrals may be relevant about how best to support an individual, but occupational therapists need to ensure that others are realistic about what can be offered.

Some occupational therapists expect that limited time and resources will result in more assessment and then consultation and training to staff and carers, though they are reluctant for it to replace direct contact with people with learning disabilities:

*“I do think we may have less client contact and more of a consultancy role, but . . . it is the therapeutic contact with clients that brings the best results.”*

As well as a growth in demand for assessment of activities of daily living referred to above, occupational therapists also experience or expect to experience increased referrals in the following three areas:

- Many of the skills assessments undertaken by occupational therapists are effectively **risk assessments**, with responses to the questionnaire indicating that 25 per cent of referrals are, at least in part, regarded as being connected with assessment of risk. There seems, however, to be a growth for some occupational therapists in the number of *specific* referrals regarding assessment of risk, particularly in relation to moves into supported living (as explained in section 3.2.3).
- With the *Mental Capacity Act 2005* (Great Britain. Parliament 2005) now fully implemented, some occupational therapists predict a growing role for them in **assessing capacity** as more people with learning disabilities move into supported living:

*“We can do the assessments for capacity regarding understanding what independent living is about.”*

- Some occupational therapists are already experiencing increased demand for **vocational and works skills assessments**, as will be discussed further in section 3.3.8 below. Generally, they describe varying levels of involvement in supporting people with learning disabilities into work, though this is seen as an important area to develop with it being focused on in key government documents (such as Department of Health 2009b):

*“Occupational therapy assessments can make a difference by fitting the person to the job or the job to the person.”*

### 3.3 Occupational therapy intervention with people with learning disabilities

The overall focus of occupational therapy on engagement in occupation and enabling independence was established in section 3.1. Within this, there are a wide range of interventions (or treatments) that occupational therapists might provide to anyone, from those with mild learning disabilities to those with profound and multiple disabilities or other complex needs. This appears to accord with the principle that occupational therapy services should be available to *all* adults with learning disabilities (OTPLD 2003).

#### 3.3.1 Long-term interventions

Although some pieces of work are short and specific, with an individual who may never be seen again, occupational therapists often describe working intensively with people with learning disabilities and having long periods of intervention of months, a year or even longer:

*“we . . . become part of that person’s life for a while”.*

Occupational therapists suggest that this long-term work is important due to learning disabilities being a lifelong condition that leads to a complexity of needs that will change through people’s lives.<sup>4</sup> Individuals are often repeatedly re-referred to the occupational therapy service. Building rapport and getting to know someone thoroughly can take time. Encouraging support workers to work in a more occupational or enabling way, means supporting attitudinal change, which is long-term work. Support workers value the extent to which occupational therapists take time to get to know them and the people with learning disabilities they support:

*“It takes a long time to build up a relationship with our type of client and for them to actually feel comfortable with you as well. . . . The [occupational therapist] has been there for a while and has got to know the clients and worked very closely with them, and I think that’s brilliant that she’s there for that amount of time.”*

(Support worker)

Occupational therapists feel that this approach enables them to be holistic and allows them to represent needs effectively to others. They describe however finding it increasingly difficult to do this long-term work, largely due to the growing pressure of waiting list targets (this will be explored in section 3.7.4).

#### 3.3.2 Skills development following assessment

Occupational therapists perceive many of their interventions as involving an element of direct work with individuals to develop their skills, for example regarding independent travel, domestic, work and community skills, particularly at times of transition. The amount of involvement following assessment seems to vary enormously across teams, with some requests for assessment to identify someone’s support needs, but then no direct role in ongoing skills development:

*“In my team, there is a real emphasis on health needs, so skills development . . . [is] difficult for me to justify.”*

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<sup>4</sup> Wilson et al (2008) stress the importance of professionals having enduring relationships with people with learning disabilities.

In some teams, occupational therapists describe skills development as sometimes being seen by other members as non-urgent work. Some find it disappointing that it may be prioritised below increasing amounts of crisis response work. A role in skills development is seen as relevant due to occupational therapists' knowledge of underlying factors, such as sensory and environmental needs:

*"We can give them realistic options because we have already assessed their strengths and limitations."*

Another participant described how her assessments are sometimes mistaken by her colleagues as teaching (for example when she is cooking with someone). She emphasised the difference between assessment (when she is learning about the person through facilitating their access to the activity) and teaching or skills development input:

*"We're not really teaching people (because we could go on forever) – we assess and gather information through activity (e.g. cooking) and facilitate other people to carry on that work."*

The consultancy role which occupational therapists often describe, facilitating others (for example families, or residential, education and day centre support workers) to support people with learning disabilities to develop skills will be explored further in section 3.4.2. Occupational therapists have a much more direct role in skills development programmes. The support workers interviewed referred to this kind of occupational therapy input.

### **3.3.3 The occupational therapy role with people with profound and multiple learning disabilities and other complex needs**

Many people with learning disabilities have what are sometimes described as 'complex needs' (CSCI/ HC/MHAC 2009). This term refers to a range of multiple and additional needs that some people with learning disabilities may have (for example physical and sensory disabilities, a dual mental health diagnosis, dementia, or epilepsy). It includes people with profound and multiple disabilities and those whose behaviour presents a challenge to services (explored further in sections 3.3.4 and 3.3.5).

Occupational therapists have an important role with people with complex needs. The specialist knowledge from the breadth of their training contributes to multidisciplinary support provided to meet these needs. In some community teams work with people with complex needs is prioritised (in line with the priority specifically given to this group of people in Department of Health 2009a).

Some describe the need to use grounded experience from a number of areas and particularly specialist skills to meet individuals' complex needs, for example:

- input into specialist dementia services for people with learning disabilities;
- work (often alongside physiotherapy) in complex seating, positioning, 24 hour posture and pressure care;
- input into a multidisciplinary eating and drinking service with physiotherapy and speech and language therapy;
- direct or consultative work regarding environmental adaptations.

Most of the support workers interviewed supported people with complex health needs and described the value of the support they had received from occupational therapists, particularly when they are able to provide long-term input with their multidisciplinary colleagues.

Where complex health needs are not related (or are only indirectly related) to an individual's learning disability, the extent to which occupational therapists in learning disability services (rather than mainstream services) should be providing input is the subject of much debate. This will be discussed further in section 3.7.3 below.

### **Engagement**

As discussed in section 3.1 above, occupational therapists focus on enabling people to have meaningful occupational lives and report getting many referrals, where others are finding it difficult to involve someone with a severe or profound learning disability in activity. This is a core reason for them to be involved with someone:

*"We lead in engagement – getting people with severe and profound learning disabilities engaged."*

They feel that a major contribution that they can bring to their teams is their ability to work with people who do not communicate verbally and report that their colleagues particularly value this skill. Sometimes input to encourage engagement in activity is directly with the individual. One participant described this as:

*"getting down on the floor with someone".*

Often it may involve supporting paid or family carers engaging someone in a worthwhile way, or pitching activities at the right level for them. The occupational therapist may therefore focus on education and training regarding the principles of engaging people in activity and the value of partial participation. Their use of sensory approaches informs this engagement work (see further section 3.3.4 below) and a key objective of intervention might be:

*"just the fact that somebody's actually engaged with them a bit more – can work with and get some response from them".*

### **3.3.4 Sensory and sensory integration intervention**

It is suggested that approximately 21 per cent of people with learning disabilities on the caseloads of occupational therapists working in community learning disability teams have sensory processing difficulties (Green et al 2003). Occupational therapists particularly note this with individuals who have a profound and multiple learning disability and/ or who are on the autistic spectrum, or have a dual mental health diagnosis. They emphasise the contribution these difficulties can make to someone behaving in a way that others can find extremely challenging.

Occupational therapists perceive meeting an individual's sensory processing and other needs as a unique component of their role and a key reason to be involved. One focus group participant put it thus:

*"The way we look at sensory things is quite unique. . . . We would look at the sensory base as for why someone's doing a behaviour that might be troublesome to*

*others. And also the way we look at finding activities for people that . . . help meet their sensory needs is quite unique."*

Identifying and meeting sensory needs is therefore a core contribution that occupational therapists can make to their teams. When addressing these needs, many occupational therapists use the theory of 'Sensory Integration' (Schaaf and Miller 2005, Green et al 2003), though only those who have taken additional post-registration training are able to offer this and funding such training is often difficult (see section 3.8.2). Those that are trained in sensory integration, refer to an increase in demand for assessment and treatment, which they feel can make a lot of difference to the lives of those referred, with behaviours changing once sensory needs have been addressed. They describe, for example, how they modify the environment in order that someone on the autistic spectrum can be:

*"in that lovely calm and alert state so they can actively engage rather than being highly aroused or under aroused".*

One of the support workers interviewed was very positive about sensory integration input saying that the person he supported remained awake and engaged for longer following this. Occupational therapists feel that sensory integration is increasingly gaining recognition both at local and national levels, as a suitable intervention for adults as well as children with learning disabilities. They see it as only relatively recently though, that key thinkers in challenging behaviour have begun to recognise the part that sensory processing plays (Department of Health 2007). In relation to those on the autistic spectrum, the importance of an understanding of people's sensory world is increasingly acknowledged (National Autistic Society 2009) and a post-registration course specifically related to sensory integration and adults with learning disabilities has been developed (Sensory Integration Network 2009).

A quality occupational therapy service that incorporates sensory integration to meet the needs of people with learning disabilities requires sufficient resourcing for there to be time to build rapport and get a true representation of the person through thorough assessment. There are examples of teams who have developed occupational therapy posts uniquely to address the sensory processing and integration needs of adults with a learning disability, though not all are as well resourced as this.

### **3.3.5 Working with people whose behaviour challenges**

In addition to the sensory expertise referred to in the previous section, occupational therapists' focus on meaningful occupation also contributes to a unique and expert role when working with those whose behaviour, for whatever reason, may be challenging to others:

*"Being bored is a key factor in challenging behaviour – you do some work with someone who is hitting and lashing out and find they have nothing structured in their day."*

Most occupational therapy input regarding behaviour seems to happen from within community teams and in education settings, however occupational therapists are included in some specialist behaviour support teams, where they work alongside others. They emphasise, however, the alternative perspective they bring with their predominant focus on occupation, looking at:

*“activities rather than the behaviour first . . . [identifying] what the person wants to do with their life”.*

Their sensory and occupational viewpoints allow them to:

*“look at it from another way rather than write the person off and say they will have to be medicated or restrained . . . there are therapeutic ways of managing these issues”.*

Occupational therapists highlight how their use of models and their assessments (see sections 3.1 and 3.2) are particularly useful in allowing them to establish what people enjoy doing and the environments most suitable for this. They will often question the structure of and level of activity within people’s days and this can:

*“really reduce the challenges because you’re allowing the person to be more active, to have more choice”.*

*“[We will] go in and question that a person shouldn’t just sit in front of the telly all day with nothing to do just rocking on a bean bag.”*

Occupational therapists describe their contribution as often preventing the need for expensive out-of-area placements, but feel that they struggle to get their important role with people whose behaviour is challenging recognised. The lack of reference to occupational therapy in a recent key document about challenging behaviour is discussed in 3.6.2 below.

### **3.3.6 Working with people at times of transition and change**

Occupational therapy involvement often seems to happen and is particularly important when an individual is at a time of transition. This term is sometimes used in a general sense to imply a change such as a move from one environment to another, perhaps where they might expect to be more independent. Responses to the questionnaire indicate that at least 17 per cent of occupational therapy referrals relate to this (see Table 2 in Appendix 2). More usually, the term ‘transition’ tends to be used to refer to older children with learning disabilities who are becoming adults and whose support needs are therefore no longer going to be met by children’s services (for example the term is used in this way in Department of Health 2009a).

Transition in this latter sense of moving into adulthood is recognised by occupational therapists as a *crucial* time and many report increased referrals relating to this period in people’s lives. Improving this experience for people with learning disabilities is a key priority of government policy (see Department of Health 2009a). Some describe very close working between children and adult services in their areas and one focus group participant highlighted her specific role working with 16–19 year olds, though she identified her post as unusual. Those working in education, such as further education colleges describe the considerable progress many students make in the time they attend. Many occupational therapists are involved with independence programmes targeted at young people coming through to adult services, particularly those with a mild learning disability. This is often in collaboration with the local adult education college, or day service. An example of such a service is a house where young people with learning disabilities live with support to develop skills with the intention of eventually moving on with less support.

Occupational therapists encounter a number of specific obstacles particularly in relation to handover from their colleagues in children's services. Limited resources mean that occupational therapy services for children with learning disabilities do not exist in all areas, particularly for older children. This means there will be no one to identify and handover needs and occupational therapists in adult teams describe discovering unmet needs when they begin assessing. Some occupational therapists feel that they have a different focus in adult services. For example, a child with profound and multiple disabilities may have had input regarding spasticity, for example customised splints. Although recognising that this work may need to carry on, occupational therapists in adult services feel that their different focus means that they do not have the resources or even necessarily the up-to-date skills to offer neurological splinting. They feel that this is a need that should generally be met by mainstream services, but some report the non-existence of such a generic service that can be accessed in their area and therefore this need can remain unmet.

Occupational therapists emphasise the impact that transition has on family carers who also experience the transition and have to adjust to the idea that their child is now an adult. Some describe an important ongoing role (both at the point of transition and later) working with parents to help them adjust to this and address any co-dependency that may exist, particularly with older family carers, whose son or daughter has lived in the family home all their lives.

Some occupational therapists describe a lack of services available to ensure that young adults (particularly, but not exclusively those with severe and profound learning disabilities) have meaningful day opportunities once they have left school.<sup>5</sup>

Acknowledging *Valuing people's* focus on the importance of transition (Department of Health 2001), one participant regretted that it:

*"never enumerated that this meant having good occupational therapists . . . supporting complex and multiply disabled people".*

### 3.3.7 Supporting people who have become parents

Some occupational therapists work with people with learning disabilities who have become parents. While at all times keeping in mind that they are working with the *parent* (rather than the child) they describe working with children's services and within child protection systems to ensure that there is:

*"marrying [of] the needs of both vulnerable groups for the best outcome for both sides".*

Many occupational therapists have no current role in this area, but can see the need for and value of becoming more involved, offering:

*"a proactive way of working with parents all through their child's life".*

This includes advocating for them having the right community support. Those occupational therapists who do not assess parenting skills *per se* do very much stress the value of their general skills assessments in ensuring that parents get an appropriate support package. They acknowledge the challenges when they are working to meet the parents' needs within a protection system where the child's needs remain paramount.

<sup>5</sup> This funding gap for day services is something also identified by the Learning Disability Coalition (2008).

One of the focus group participants described her role as lead of the special parenting service in her community team. She felt that this would be a positive direction for occupational therapists across the country.

### **3.3.8 Work skills, vocation, supported employment**

Occupational therapists see a huge potential role for them in moving forward the government agenda in *Valuing employment now* (Department of Health 2009b) for people with learning disabilities to gain work skills and paid or unpaid employment. They describe the benefit of using their assessment skills, as described in section 3.2 above, to identify people's abilities and support needs in order to enable accurate job matching, job adaptation and grading of activities within the work environment:

*“Occupational therapy assessments can make the difference by fitting the person to the job or vice versa and picking up the very specific things the person needs.”*

The level of current involvement in this area varies a lot from team to team. In the focus groups one occupational therapist spoke of providing training to individuals' workplaces about their needs and how this was making a real difference to the success of placements and jobs. Another described the increased demand she was getting for vocational skills assessments, though she was struggling to find the capacity to meet this demand.

There seems to be some uncertainty about how occupational therapy should sit within and link with the other work agencies (for example local supported employment services). One suggestion is that work services could support most people and that occupational therapy could become involved on a consultancy basis where there are more complex barriers to someone getting a job or work placement.<sup>6</sup>

## **3.4 Working with others to meet the needs of people with learning disabilities**

Within their teams, occupational therapists work alongside other health and social care practitioners, such as social workers, learning disability nurses, speech and language therapists, physiotherapists, psychiatrists and psychologists. They often provide a consultancy role to these colleagues as well as to families, support workers and mainstream services.

### **3.4.1 Integrated learning disability teams**

Occupational therapists perceive collaborative working as good practice. Whether the health and social care parts of their teams are wholly integrated or not, they favour being based in the same building, as this enables a more fluent dialogue. Information and knowledge can be shared on issues such as the quality of a service commissioned to meet an individual's needs:

*“When you are together and you know the constraints, you can have good honest and open discussions.”*

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<sup>6</sup> The Foundation for People with Learning Disabilities (2005) have identified that the current system for supporting people into employment discriminates against people with severe learning disabilities and this consultancy idea means that occupational therapists could have a role in widening access to work opportunities.

With the range of disciplines easily accessible, multiprofessional interventions are possible. This is also a form of support and learning. Integrated teams enable an increased understanding of respective roles which impacts on the quality and quantity of referrals received. Occupational therapists can stress the importance and value of occupation and complex cases can be discussed in team meetings allowing everyone involved to work out the best way forward.

Occupational therapists give examples of joint working with all other members of their teams, including speech and language therapists regarding communication or eating and drinking, physiotherapists regarding positioning and nurses regarding epilepsy.

In some areas, however, teams that used to be integrated have reverted to separate teams:

*“We used to be social workers and health professionals in the same office, we had everything joint and it worked really, really well. They changed all that and it’s really difficult now . . . I mean we want that back.”*

### **3.4.2 Working with support workers and family carers**

An important aspect of the occupational therapist’s role is working with paid and family carers, in a variety of settings including people’s own homes and in day, residential and supported living services. One support worker reinforced this by stating:

*“We tend to work quite closely with the team and they all work very closely with each other.”*

This role includes providing consultation to teams of support workers and making achievable recommendations following occupational therapy interventions. This consultative role means supporting staff teams to develop skills in engaging people with learning disabilities in activities and to *plan* what is happening in people’s days, including offering training. A good provider, a good team of staff and a good team leader need to work effectively together as:

*“It’s the pulling together of everybody that actually makes some significant change for somebody.”*

Motivating staff teams improves job satisfaction for the occupational therapist:

*“[It inspired] a staff team into providing a whole new approach with others in the house . . . (It) made my job nicer.”*

Limitations of time and resources mean that occupational therapists believe that providing consultation and training to support workers is likely to be an increasing part of their role. Experiences of working with support workers and their managers vary greatly with some reflecting on the positives and others emphasising some of the challenges.

The findings of this section predominantly relate to support workers rather than family carers partly because these are the people who were interviewed, but also because the occupational therapists, despite referring to the importance of working with family carers, mainly discussed support workers.

### **Achievable recommendations for support workers to follow**

A core component of occupational therapy is to discuss and provide recommendations for others to follow. Both support workers and occupational therapists emphasise the importance of the recommendations being achievable. How achievable they are can depend on the nature of the team that will be following them:

*“It’s often a compromise because you’d like to implement all sorts of wonderful things and you have to be realistic about the abilities, the staffing levels and the skills of the people you’re leaving it to.”*

Some factors are particularly influential in motivating support workers to follow recommendations made, in particular, a positive outcome for the person with a learning disability. This could be a notable increase in independence, an increase in choice, or an improved routine and is often a result of the person with a learning disability, family carers, support workers and the occupational therapist working together in order to achieve the desired goal.

Negotiating with staff teams and taking their views on board without dictating to them makes it more likely that recommendations will be followed. Involving support workers in the planning of sessions, discussing improvements and regularly reviewing occupational therapy input with them are essential and one support worker liked the fact that:

*“Recommendations are never given at face value and . . . told to get on with it. The [occupational therapist] will ask ‘is there anything I can help with?’.”*  
(Support worker)

### **Working relationships with support workers**

Generally, close working between all professionals within the learning disability team is deemed important by support workers, such as them being:

*“on the end of the phone – we work very closely with the team and they all work very closely with each other.”*  
(Support worker)

Developing a good working relationship with key members of staff who have particular interests or skills can increase the likelihood of recommendations being followed. Some are keen to develop their personal skills within their workplace, though it is vital that occupational therapists also consider how knowledge is to be spread across the *whole* team.

As well as including support workers when developing recommendations, it is important that managers are also involved. One support worker, who also managed a service, was clear that they wanted to be involved in how recommendations were communicated to staff. Nurturing links with managers of establishments can lead to them being more willing to roster on consistent team members such as those with skills or interests that are particularly relevant to the occupational therapy intervention.

Putting recommendations in writing to clarify the key points discussed and agreed is important, though this needs to be in an accessible format. Support workers emphasise the importance of occupational therapists keeping recommendations down to a minimum:

*“so people aren’t confronted with huge lists of instructions . . . plain and very basic”.*

*(Support worker)*

They value being involved in the decision about the format of recommendations in order that they are transferrable to a whole staff group. This may mean looking beyond written guidelines and recommendations that are not always followed and giving support workers alternative tools, including visual materials such as a DVD.

When working with support workers occupational therapists need to be appreciative and understanding of their circumstances. This includes appreciating that as occupational therapists, they only visit briefly, whereas support workers are involved for longer periods of time.<sup>7</sup>

### **Resources available to those supporting people**

Resources can impact on whether an establishment is able to carry out the recommendations arising from an occupational therapy intervention. As highlighted in 3.2.2, it may be necessary to advocate to social care that an individual needs more or different support to that they are currently getting. Increased resources, or changes to staffing or rotas may then be possible.

Both occupational therapists and support workers often refer to the difficulty of retaining support staff due to low wages and other employment opportunities that pay better:

*“[those] working with people with profound and multiple needs . . . are paid the minimum wage. I am astounded they are paid so little.”*

When there are personnel shortages, there is often an increased use of bank and agency staff. It can be difficult for bank and agency staff working with people with learning disabilities on a short-term basis, particularly when working with those with complex needs. It can lead to many different support workers implementing occupational therapy recommendations, not all of whom may have read support plans which can affect the outcome of the intervention. People with learning disabilities are then not supported consistently and can become distressed. Some occupational therapists are involved in creating ‘passports’ containing the essential information that anyone new to that person will need when supporting them for the first time.

### **Enabling support workers to develop their skills**

Government documents (e.g. Scottish Executive 2000, Welsh Assembly Government 2007 and Department of Health 2001) acknowledge the training needs of those supporting people with learning disabilities. There seem however to remain few opportunities for training, and occupational therapists highlight deficiencies in the National Vocational Qualifications training that is available. They feel that further investment in training of support workers would allow occupational therapists’ time to be used most efficiently.

Occupational therapists provide a broad spectrum of both formal and informal training, either by themselves or with other members of their multidisciplinary teams. This may consist of rolling programmes or occasional training as required. Workshops often cover the value and importance of occupation and participation in activity and the skills of

<sup>7</sup> Wilson et al (2009) highlight the conceptual and emotional challenges when working with people with severe and profound learning disabilities.

how to support someone to be more engaged, sometimes using the framework of 'Active Support' (Stancliffe et al 2007). Other areas include travel training, dementia, eating and drinking, and autism. Support workers describe finding these beneficial, with one interviewee particularly valuing training around suitable activities in which to engage people with profound and multiple learning disabilities.

When planning training with support workers, occupational therapists highlight various factors that need to be considered. These include the values of the individual service, how willing support workers are to consider alternative options and the extent to which they perceive themselves as separate from local planning and preferring to work in isolation.

The occupational therapist needs to ensure staff teams implement what they have learnt and identify whether there are any further training needs. One way of improving the effectiveness of training is for a specific support worker and the occupational therapist jointly to plan and lead it. Some support workers are enthusiastic about this prospect:

*"[Sensory integration] is something I would like to become more involved in, to put together some training packages."*

*(Support worker)*

Occupational therapists have varying views about the impact of training on their roles:

*"We are good at teaching support staff and happy to pass on skills to whoever can make the person's life what they want it to be."*

*"I feel there may be a greater uptake of training. However, I hope this is not seen as a cheaper option (to face to face contact with the service users) or will replace physical contact with this client group."*

### **3.4.3 Collaborative and consultative working with mainstream services**

Developing a working partnership with those in mainstream health and social care services is important to ensure that the needs of people with learning disabilities are met and this is part of the advocacy role referred to above in section 3.1.7. Occupational therapists describe joint working with their fellow occupational therapists in for example, working age and older people's mental health teams, acute hospital and physical rehabilitation teams and wheelchair services (see Table 5 in Appendix 2). One focus group participant illustrated this:

*"We had one gentleman we were working with and he had physical needs as well . . . when the social services occupational therapist went out he said no I'm fine and he clearly wasn't and you could see the state of the house and everything else. Actually it's not fine, so we ended up going back and doing joint visits."*

A high proportion of respondents to the questionnaire highlighted the joint work they do with occupational therapists working in social care. Input (for example during joint visits) may range from advising on appropriate environments for people on the autistic spectrum, to enabling others to understand the individual's learning disability. It can involve enabling a person with a learning disability to make choices and communicate their needs or jointly assessing whether it is the learning disability that is affecting function or something else.

Respective roles seem predominantly to be negotiated informally on a case-by-case basis with not all areas having formalised pathways or protocols setting out the responsibilities of each team (as suggested in OTPLD 2003). Some teams are in the process of developing these, although they highlight difficulties:

*“We have tried to draw up a document with the community occupational therapists re. integrated working practices, but it is difficult to pin down in practice. When waiting lists get too long [the social care occupational therapists] tend to see aids and adaptations as our core business.”*

The occupational therapist’s consultative role also extends beyond fellow occupational therapists. It includes advocating for people with learning disabilities by supporting them to access services such as contacting local bus drivers so they understand people’s needs. The breadth of this consultative role of occupational therapists is illustrated in Table 5 in Appendix 2.

### 3.5 The outcomes of occupational therapy with people with learning disabilities

Occupational therapists feel they achieve good outcomes following the specific assessments and interventions referred to above. Outcomes are improved if there is a good working relationship with the person with the learning disability, family carers, support workers and other team members. Outcomes may be difficult to measure due to there being a limited number of tools that indicate change accurately in people with learning disabilities.

#### 3.5.1 Good outcomes

Addressing the reasons for referral may lead to a long-term sustainable solution, but due to the nature of the work, people are often re-referred:

*“Every few years something is going to slip and you’ll get a re-referral, but with good record keeping you can go back and it saves a lot work.”*

A good outcome may not just mean achieving the reason for referral, as the intervention often evolves while working with the person. The perspective of the person with a learning disability, family carers and support workers on what the outcome should be and whether it has been achieved is particularly important, for example their satisfaction with their own occupational performance:

*“The person has achieved something . . . they wanted to achieve . . . you’ve made a difference to their quality of life and enabling people to move on and be more independent . . . we’ve enriched their quality of life and that of the carers . . . not just seen them and ticked the box.”*

With their increasing consultative role, occupational therapists feel they are ever more dependent on support workers to achieve a good outcome, as discussed in section 3.4.2. This is particularly apparent for people with profound and multiple learning disabilities where much of the work could be via a support worker or family carer.

The attitudes of the person with learning disabilities, support workers and their family carers towards promoting independence also affect the quality of outcomes. Family

carers are important in facilitating development of new skills in liaison with the occupational therapist, though occasionally the success of this may be influenced by whether the family has accepted that they have a son or daughter with a learning disability. One participant described a situation where:

*"[A mother] can't cope with the fact that she has a daughter with a mild learning disability and she either disables her more or expects her to be perfect."*

Different professionals are often working on different aspects of a person's needs and this joint working brings the benefit of different perspectives in order to achieve a meaningful outcome. Relationships are key to ensuring that the various professionals are all working towards a similar aim, though it can sometimes be difficult to isolate individual contributions to the overall team outcome.

### **3.5.2 Measuring outcomes**

Measuring outcomes can be a particular challenge when working with people with learning disabilities. Improvements in quality of life can be hard to quantify and occupational therapists feel the need to find ways of evidencing subtle changes. It is also not always clear who the outcome is being measured for – the person with learning disabilities themselves, their family, support workers, or service commissioners.

Documenting whether aims of intervention set at the outset have been achieved is an important way of demonstrating outcomes. The majority of respondents to the questionnaire (see Table 6 in Appendix 2) indicated that they had met these with the last three cases they had discharged from their caseload. Those that had not achieved the aims cited a variety of reasons including the person with the learning disability choosing not to engage, resource and time limitations, as well as in some cases, a lack of co-operation or support from others as described above.

Some occupational therapists have created their own outcome measures (for example using questionnaires to demonstrate impact of an intervention, or using photos to establish change in an individual's degree of comfort or relaxation). As discussed in section 3.2.3 above, there is a particular lack of standardised tools that can be used to measure outcomes in relation to people with profound and multiple learning disabilities. Tools with a greater focus on the environment and which are sensitive enough to measure change in this group of people would be beneficial.<sup>8</sup>

## **3.6 Recognition of occupational therapy with people with learning disabilities**

Recognition of the occupational therapy role by fellow professionals within both health and social care assists in ensuring that the needs of people with learning disabilities are met. Ensuring that all assessments and interventions are based on the best available evidence (Department of Health 1998) supports recognition of the profession, while limiting the blurring of roles with other professional groups.

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<sup>8</sup> This need for objective outcome measures is supported by Jerosh-Herold (2005).

### 3.6.1 The evidence base for occupational therapy with people with learning disabilities

Occupational therapists recognise the importance of evidence-based practice on a day-to-day basis and when considering new methods of working:

*“We want to be proactive about what we deliver rather than just reacting to referrals we receive.”*

There is however limited published research evidence to support clinical practice, which was the original reason for this study being commissioned. There is a particular need for evidence on the effectiveness of occupational therapy interventions and regarding assessments and outcome measures.

With few specific textbooks (Goodman et al 2008 being the only up-to-date example), or other guidance and few ‘gold standard’ trials, much of the evidence is within clinical practice. This has required occupational therapists to utilise their creative nature and to be innovative, as described in Section 3.1, though at the same time it:

*“maybe makes us more confused – what should we be doing, what should our priorities be?”*

Such specific guidance as is available from the College of Occupational Therapists and its Specialist Section – People with Learning Disabilities (for example the standards in OTPLD 2003) seem to be interpreted in different ways depending on geographical location. Increasing the evidence base could allow occupational therapists to provide a more consistent service and strengthen their position in multidisciplinary teams:

*“Something which is taken as a consensus of what [occupational therapy with people with learning disabilities] is all about . . . to bring it together in a master document and get some guidance from that would be fantastic.”*

There are few occupational therapy research posts or split clinical/research posts, when compared to other disciplines such as psychology and there is currently only one consultant occupational therapist post within learning disabilities in the United Kingdom. This can create difficulties in ensuring a link between researchers and practitioners.

Respondents to the questionnaire were asked what would inform their practice. They suggested research in a wide variety of areas from specific interventions, such as standardised assessments and sensory integration, to the occupational therapy role with people with additional needs such as dementia, mental health issues and autistic spectrum disorders (see Table 8 in Appendix 2).

#### Obstacles to creating the evidence base

There are several obstacles to developing this evidence base for occupational therapists working with people with learning disabilities. Despite the general consensus that more published research is required, some occupational therapists perceive themselves primarily as clinicians rather than researchers:

*“When it gets down to sitting down and putting a pen in my hand or typing at a computer, I’d much rather be with my clients than doing that quite honestly.”*

*"We are so busy doing what we're doing that there isn't time to explain and create the evidence base."*

A workplace environment or culture is needed where spending time creating the evidence base is accepted and encouraged. Support from line managers is needed to develop services and overcome the obstacles to participating in research. Dedicated time is needed to read literature and to network to share best practice as well as time to undertake research, though many occupational therapists describe a lack of opportunity, due to the pressure of waiting lists and targets. Even if they do complete research, perhaps as part of a Masters programme, there may not be time to disseminate it. The issue therefore seems to be not only a general lack of research, but also a lack of publishing of the research that *has* been carried out, which can lead to:

*"an awful lot of really valuable work going on where we are all repeating the same things basically".*

Occupational therapists suggest that it would help if the College of Occupational Therapists Specialist Section – People with Learning Disabilities were to co-ordinate a library of existing resources as a way of sharing good practice and saving duplicated work across the country. This could include grey literature and anecdotal evidence as well as published research, case studies and resources such as adapted recipes, which would avoid repeated reinvention.

### **3.6.2 Recognition by others**

Occupational therapists identify other factors that contribute to their recognition more widely within the learning disabilities field.

#### **Recognition within community teams**

Most occupational therapists feel appreciated and valued within their multidisciplinary teams and some feel they are viewed as innovative. They believe however that the profession does not always get the recognition it deserves, especially when new services are being developed:

*"We don't get the recognition of being a core service. We are not a luxury, icing on the cake – we add core value to the [learning disability] service and have a very skilled and meaningful role."*

This may be due to a feeling that their profession has tended not to have as strong a management structure within learning disability teams as their nursing and social care colleagues traditionally have had. This means that occupational therapists have to work hard to ensure that their managers have a better understanding of their roles and the value of occupational therapy to the team and people with learning disabilities.

There is variation nationally as to who manages occupational therapists or to whom they are professionally accountable. Generally it seems that they are line managed by the budget holder of their service. This means that as integrated health and social care learning disabilities teams have evolved, occupational therapists are increasingly line managed from within the team rather than from within their profession by a Head Occupational Therapist or Professional Lead. Being managed by a team manager who is most likely not an occupational therapist can present both challenges and opportunities:

*"I've had to train . . . managers who aren't occupational therapists and sell . . . the value of what I do . . . you have to put yourself out there a little bit more. But I think it's good because they've had no preconceived ideas whereas my previous . . . [occupational therapy] manager thought she knew what I should be and shouldn't be doing. . . ."*

### **Wider recognition**

Occupational therapists also note limited recognition for their profession's role with people with learning disabilities more widely in NHS social care and in policy documents. Key national documents (e.g. Department of Health 2009a and Scottish Executive 2000) emphasise the importance of the areas that occupational therapists focus on, such as meaningful activity, routines and the environment, but occupational therapy expertise is rarely acknowledged, or recognised:

*"We try to influence policy makers and service planners and have a significant amount of information we can give here, but it is quite often not listened to."*

This lack of national recognition impacts on occupational therapists locally. For example, one participant described how the absence of specific mention of occupational therapy in recent key national guidelines regarding challenging behaviour (Royal College of Psychiatrists et al 2007) meant that occupational therapy was not recognised locally. She therefore had:

*"a battle to get occupational therapy recognised, as local documents were based on national documents that did not recognise [us]"*.

Although the absence of reference to occupational therapy in that document has been addressed by the College of Occupational Therapists (COT 2009), this highlights the need to define and promote a clear role and input into government documents and other national strategies.

### **3.6.3 Confidence and assertiveness in the role**

A major theme is the need for occupational therapists to be confident and assertive about their role, although some describe the limited evidence base or clear consensus of the role of the learning disability occupational therapist as making this more difficult. Specific written referral criteria, leaflets and formal protocols can help them to be increasingly clear and assertive and to educate their teams about their role:

*"We're getting much stronger and more assertive in saying this is what we're doing."*

Integrated team managers with a good understanding of the role of the occupational therapist can then use these criteria to screen referrals enabling a team decision to be made about the appropriateness of referrals rather than therapists making that decision in isolation. When requests are received for intervention outside these criteria, it is important to signpost the referrer to more relevant services. An example of this is passing referrals for property adaptations that require Disabled Facilities Grant applications to social care occupational therapists as this is *their* area of expertise.

### Using appropriate terminology

Acknowledgement may be increased by ensuring use of appropriate language to explain the occupational therapy role. During professional meetings and discussions it may be appropriate to draw on the language of, for example, the MOHO or occupational science to demonstrate the complexity of clinical reasoning. Failing to do this can give a false impression of occupational therapy being an easy role to undertake. In contrast to this it may be important when advising family carers and support workers to reduce jargon or scientific language and explain in a more simple way.

When writing reports this balance can be difficult to achieve. If a report has been written in an accessible format to enable it to be understood by someone with learning disabilities, another professional (such as a GP) may not then recognise the significance of the occupational therapist's contribution:

*"[We are] trying to plot the line between something families and individuals will understand and something that does us justice professionally."*

Some occupational therapists avoid this by writing two reports, one for other professionals in full and one for the person with a learning disability using simpler language, though this approach is not supported in all teams, due to the increased time involved.

### Defining and promoting the occupational therapy role

Being clear and assertive about occupational therapy prevents the role from becoming blurred and reduces the expectations to take on extended or generic roles such as care management that result in less time for specialist input. This is discussed in more detail in section 3.7.3 below.

Regular attendance at multidisciplinary referral meetings assists in promoting the role:

*"It's a good learning experience because other members of the team hear what people have been referred for and say 'oh you do that do you?'."*

Generally, the profile of occupational therapy in this area is raised by ensuring that occupational therapy is represented on relevant learning disability and profession-specific sub-groups and forums within the organisation.

## 3.7 Impact of wider health and social care policy on occupational therapy with people with learning disabilities

Government policies related to people with learning disabilities influence the work of occupational therapists. It has been seen that many of the outcomes of occupational therapy interventions are closely linked to the priorities in these policies, as outlined in section 1.1:

*"I think when Valuing people [(Department of Health 2001)] came out for us as [occupational therapists], a lot of the stuff they were asking us to do, we're actually already doing anyway."*

Wider initiatives that also impact on occupational therapists' work include the integration of health and social care teams (Department of Health 2009c), waiting list targets (DHSSPSNI 2009) and eligibility criteria (Department of Health 2003).

### 3.7.1 Priority of people with learning disabilities

Occupational therapists perceive that despite the afore-mentioned government policies and strategies, people with learning disabilities remain low on local and national agendas. They refer to insufficient funding attached to the strategies for their aims to be achieved:

*"I do think we miss out by not having specific targets, clear guidance as we might have if we worked under a NSF [National Service Framework]."*

Learning disability services are often a small speciality, viewed by some as a:

*"Cinderella service – we're all such tiny fish in the bigger system".*

### 3.7.2 Resources

#### Social care funding for support

Occupational therapists have no budget to fund any recommendations they make regarding an individual's support package, which can be a challenge. In the current financial climate, they describe significant cutbacks in services provided to people with learning disabilities. They may wish to implement a support package but report a lack of funding. They describe the time they spend negotiating with funding panels for relatively small care packages which can be frustrating when their own resources are so limited.

Support workers also emphasise the impact of limited financial resources on the services in which they work and their feeling that practice is led by financial restrictions rather than individual need. This can result in occupational therapy recommendations not being followed due to insufficient resources for specific activities, reduced levels of support, or transport problems. As one support worker stated regarding an occupational therapy recommendation:

*"Sensory integration is not something we could do on a daily basis . . . we do not have a great deal of resources."*

*(Support worker)*

Occupational therapists report an increase in referrals specifically to reduce expenditure, for example:

*"If a person doesn't do a road safety assessment, funding will be withdrawn for a taxi . . . it is not the person with a learning disability who has asked for this assessment . . . it is not the way we like to work with people."*

There are conflicting views on this as some occupational therapists feel it puts them in a strong position to sustain their role while others query whether the person is consenting to the assessment.

Financial resources also impact on availability of appropriate placements, for example the number of vacancies in good supported living or residential schemes.

### Care management

It could be perceived that taking on more of a care management role would be a way of solving the difficulties around occupational therapists not being able to access resources. Some describe feeling under increased pressure to take on care or case management and/or sense that this is likely to be a future direction in their services. Reactions of occupational therapists are however consistently against this idea and often very stridently so:

*"We've got a lot of concerns that that will happen with our redesign, but we're fighting it."*

They are concerned about a possible conflict of interest and compromise to the independence of the occupational therapy assessment were a broader role such as care management to be undertaken, as financial limitations may compromise what is best for the individual. Although they feel that they have the professional expertise to be good care managers, the consensus seems to be that it is not the best use of their skills.

### Shortage of occupational therapy posts

Occupational therapists in many areas are sole practitioners within community learning disability services and many highlight a shortage of occupational therapy posts, which limits what they can achieve:

*"There are not enough hours in the day to do all the things you could be doing."*

Additional occupational therapy resources would allow more time for specialist input in the areas described earlier in this report. In some areas, funding shortages have led to occupational therapists having to limit what they can take referrals for and the teams they can take referrals from. Sometimes when posts become vacant, they are frozen, though were they to be unfrozen or new posts created, occupational therapists do not think there would be difficulties recruiting into them. They have some concerns, however, surrounding the levelling out of grades with many NHS posts being at Band 6 following Agenda for Change (Department of Health 2004) leading to a very flat organisational structure within teams.

Support workers acknowledge the limited number of learning disability occupational therapists, with one stating that:

*"If they had more finances we would use [occupational therapists] more."*  
(Support worker)

### 3.7.3 Social inclusion and enabling access to mainstream services

One priority across all four countries (Department of Health 2009a, Scottish Executive 2000, National Assembly for Wales Learning Disability Advisory Group 2001, DHSSPSNI 2005) is that people with learning disabilities have the right to access mainstream or generic services and should not have all their needs met by specialist learning disability services. Occupational therapists agree with this assertion and use these documents to support their efforts to enable people to access mainstream occupational therapy services.

### Specialist skills

Occupational therapists emphasise the need for them to concentrate on a person's needs related to their learning disabilities and promote inclusion into mainstream services for other needs (OTPLD 2003):

*"[We are] moving towards trying to be more specialised and only look at problems where we are actually using those specialist skills – us doing what nobody else can do or will do."*

Through concentrating on interventions that utilise the occupational therapist's specialist learning disability skills, more attention can be paid to areas such as productivity, leisure and sensory integration, which makes the best use of their limited resources. If occupational therapists attempt to be experts in all clinical areas outside their speciality they may not be up to date with current developments or have the relevant experience. Not accessing mainstream occupational therapy services can then impinge on the quality of service people with learning disabilities receive:

*"[A person with a learning disability] has as much right to use the expert as everyone else."*

*"We're really specialist in learning disabilities, but good practice also means we need to go to other people who are specialist in other things."*

There is recognition that accessing a mainstream service, such as for a Disabled Facilities Grant, may result in people waiting longer than they would if they were to have all their needs met within the learning disability service. This however can be seen as part of inclusion in society, as people with learning disabilities should be prioritised on a waiting list alongside others (for example those with physical disabilities).

Some occupational therapists note the impact of pressure to undertake more generic roles:

*"In the area I work in, [occupational therapists] have very little time to do what we would consider specialist [work with people with learning disabilities] because they're care managing, having to find accommodation, day care, arrange respite etc."*

Failing to undertake and promote a specialist occupational therapy role focusing on people's learning disability-related needs risks loss of professional identity. Marketing services seems to be an area that some occupational therapists lack confidence in:

*"Occupational therapists are poor at marketing themselves. They expect others to take what they can contribute at face value. . . . The modern occupational therapist must become more adept at [this]."*

### **Still 'doing equipment'**

Despite the clear guidance (OTPLD 2003) and what generally seems to be a strong wish to focus on learning disability-related needs, assessing for provision of equipment or adaptations to meet physical disability-related needs, still dominates the caseloads of some occupational therapists in learning disabilities teams. There is a huge variation in this across the United Kingdom and even between neighbouring services, with some concentrating on specific learning disability assessments and others placing the emphasis on seating, wheelchairs and adaptations. One participant stated:

*"We won't do [Disabled Facility Grants] in the team I work in but [learning disability] colleagues in [neighbouring county] will."*

This seems particularly to be an issue in Northern Ireland which has a different health and social care structure to the rest of the United Kingdom. One participant from Northern Ireland commented on the fact she is expected to be a:

*“jack of all trades”.*

Suggestions are made as to what has prevented guidance from being more influential in reducing the amount of equipment and adaptations work completed by occupational therapists in learning disability teams. Some occupational therapists encounter obstacles from their counterparts in mainstream health and adult social care services, who may expect that if someone is known to the learning disability community team, they will receive all their occupational therapy from there:

*“People say, well you have all had the same training so why can’t you do these sort of tasks as well?”*

*“We are under increasing pressure to provide both minor and major adaptations which the local [social care] occupational therapists refuse to supply.”*

With some learning disability occupational therapists focusing on adaptations and equipment, there is a risk of diluting the specialism and work regarding the broader aspects of independence being neglected. Occupational therapists need to be able to clearly define their unique role and specialist skills.

*“We are in danger of having the skills diluted because we’re doing so many things – as a group we need to nurture the specialism.”*

### **How to establish a specialist learning disability occupational therapy role**

Services that had the most success in carving out a specialist role for themselves and enabling access to other services for non-learning disability-related needs, have found that being assertive and persevering about this is vital:

*“It’s not something that we solved overnight – this is years and years of work”.*

In order to establish this specialist role, occupational therapists need to be clear and strong about what they do, as described in section 3.6.3. They need to recognise the expertise of other occupational therapists and support them around an individual’s learning disability. Education of other occupational therapists as well as partnership working with mainstream services builds up their knowledge and skills in working with people with learning disabilities. This partnership working can be achieved by presenting the learning disability occupational therapist’s role and specialism to other services. Formal protocols with other health and social care occupational therapy services regarding respective roles should also be explored (as recommended in OTPLD 2003). A frequent means of partnership working with mainstream occupational therapy colleagues includes joint visits to ensure that a specific person gets the benefits of both areas of expertise:

*“If you’ve got two people there – an [occupational therapist] who is community-based and very skilled in equipment and adaptations alongside an [occupational therapist] who is very skilled with the sensory process and the challenging behaviour, it actually gives the person the best of both approaches.”*

*“We’ll gladly go in and support the [occupational therapist] – the right [occupational therapist] – to make sure someone’s [learning disability] needs are accounted for.”*

### 3.7.4 Eligibility and targets

The benefits that occupational therapists perceive from being able to work with people over long periods of time were discussed in section 3.3.1. Increasingly, however, changes related to eligibility and government targets regarding waiting lists mean that:

*“It’s people very much referred for a specific reason and then once dealt with they’re closed.”*

Some members of integrated learning disability teams are employed by the NHS and others by the local authority. Different policies and eligibility criteria can cause confusion to professionals, family carers, support workers and people with learning disabilities:

*“The eligibility criteria are being debated between the NHS and Social Services as the definition of complex needs cannot be agreed. This is impacting on my work as my Social Services colleagues may not pick up cases that the NHS occupational therapists and nurses might want to refer to them in the future.”*

Occupational therapists are concerned that pressure on resources and adoption of eligibility criteria such as Fair Access to Care Services can mean that some people who require support from learning disability services do not receive it. They feel that this results in more crisis response rather than preventative work, which may result in more expensive support packages being required later:

*“It’s kind of fire fighting . . . social workers only meet people’s needs that are critical or substantial . . . people on the lowest bands are neglected yet occupational therapists can help them . . . avoiding problems later on.”*

Additionally, many occupational therapists across all four countries of the United Kingdom find themselves increasingly affected by waiting list targets, with this particularly seeming to pose a challenge for those working in Northern Ireland. The impact of these targets can be strict limitations on work undertaken. Examples of these include only being able to work on the needs stated on the referral, whether or not these are important to the person, or a restricted role such as only being able to work with people who have complex needs:

*“We have such a range of skills, so many people could benefit from occupational therapy but we have to prioritise and think to what extent do we get involved? . . . You can’t follow through a proper holistic approach . . . people shout at you to see the next case and tick that box . . . meaningful results are diminishing.”*

Very strict targets around the time taken to respond to referrals create constant pressure to remove people from the waiting list and onto huge caseloads. Occupational therapists describe their strong feeling that such directives focus attention on quantity of referrals rather than quality of service. These targets make long-term occupational therapy, such as sensory integration, difficult as they limit the time available for

treatment or intervention. Occupational therapists describe not enjoying this method of working, which they feel does not fit with their training, which emphasises a good outcome as being a difference to an individual's quality of life and not just the fact that they have been seen. The approach is felt to stem from a medical model that is not appropriate for people with learning disabilities who:

*"aren't sick, you don't just treat them and they get better, they need support over a long period of time".*

## **3.8 Developing the necessary skills to work with people with learning disabilities**

### **3.8.1 Learning disabilities in occupational therapy pre-registration training**

#### **Content of occupational therapy training**

With the focus today on enabling access to mainstream services (as described in section 3.7.3 above), an occupational therapist will increasingly need skills to work with people with learning disabilities in whatever setting they are working in. When discussing the content of their professional pre-registration training, however, occupational therapists consistently describe their perception that there has been and still is very little specific content on working with people with learning disabilities. They do acknowledge a slight improvement in this, but emphasise that it should be given a much higher profile:

*"There is a very little bit on learning disabilities and it would be tied to paediatrics, but not nearly sufficient to inform people of the sorts of skills an [occupational therapist working with people with learning disabilities] would need to be thinking about and developing."*

Many occupational therapists have the impression that unlike an area such as mental health, content about people with learning disabilities is often minimal, or even optional and generally neglected. They believe that whether courses cover this area more thoroughly may depend on whether one of the lecturers has a background in this area.<sup>9</sup>

Occupational therapists feel that there is a need for pre-registration training to be developed to ensure that content, in this area is up to date. This needs to include addressing general public assumptions about people with learning disabilities and the role of the occupational therapist. One focus group participant recommended that people with learning disabilities should be involved in training where possible and stated that:

*"there's something about actually meeting someone with a learning disability".*

#### **Student placements**

Some occupational therapy students gain experience of working with people with learning disabilities on one of the practice placements during their training. Many occupational therapists describe getting very good feedback from students about such

<sup>9</sup> The understanding that there are no set standards about what people should learn about working with people with learning disabilities is confirmed by the recent Ombudsman's report (Great Britain. Parliamentary and Health Service Ombudsman 2009).

placements, which allow students to develop the relevant knowledge and skills. Those who offer regular placements also find that their services benefit in terms of keeping up to date with the latest developments.

Sometimes students can be wary of working in this field and do not expect to enjoy the placements, but occupational therapists find they are often surprised how much they take to working with people with learning disabilities. Placements can therefore be an important source of future recruitment:

*“That’s how you convert [people] though – when we have them as students they get completely hooked.”*

*“I wouldn’t have thought to do it if I didn’t have a placement.”*

Another general perception among occupational therapists, however, is that too few student placements are offered by teams where students can gain experience of working with people with learning disabilities. Lone occupational therapists describe finding it difficult to take students regularly. As working with people with learning disabilities has become more community-based and less buildings-based, some teams feel they can only take more experienced students for their final placement. One focus group participant described getting round this by having the student based for part of the week in an adult resource centre to help them build their core skills.

One issue identified by occupational therapists that impacts on the number of student placements available is that some universities divide their placements into physical and mental health and tend to assume that learning disabilities falls into the mental health remit. They describe it as naive that there is not even an expectation that a placement would not fall into one of those categories as their role with people with learning disabilities encompasses both areas and more.

### **3.8.2 Post-registration learning**

Occupational therapists identify the need for ongoing development of their skills post-qualification in order for them to be able to work effectively with people with learning disabilities

#### **Moving into learning disabilities**

Occupational therapists’ views differ on whether the area of learning disabilities is suitable for novice practitioners. Some insist that more grounded experience should be gained first due the length of time it takes to learn the role and to it being a complex speciality where it is necessary to draw on a variety of knowledge. There appear to be very few fixed or rotational posts in learning disability teams for new or recently qualified occupational therapists. Those few posts that exist tend to be filled by people who have had previous experience of working with people with learning disabilities, as it can be difficult to provide enough support for newly qualified occupational therapists to develop their core skills.

There is disagreement about whether newly qualified rotational posts can be successful in community learning disabilities teams. Some do however describe successful rotations (often for a year rather than six months) and feel that they can raise the profile of occupational therapy with people with learning disabilities within the overall service. Some feel that rotations tend to work better where the role involves substantial input into day services or an inpatient unit, for example an assessment and treatment unit.

One of the support workers interviewed referred to the benefit of this, though they also expressed the point that short rotations may not allow sufficient time to get to know people.

This means that practitioners often have to learn the skills at a more a senior level when they feel that they are expected to know more. With most posts being at senior level in this field, one participant questioned:

*“How do we get new blood in?”*

When moving into learning disabilities from other areas of practice, some occupational therapists describe surprise at the complexity of the demands placed on them. Focus group participants described the move as daunting and discussed the length of time it took to feel confident and experienced. One participant stated:

*“It was almost like hitting the ground running – the learning that had to be done, an upward hill the whole time.”*

### **Lack of specific ongoing training opportunities**

Occupational therapists find that, with the exception of perhaps sensory integration, there is very little specialist post-registration training available to them that is specific to both learning disabilities and occupational therapy:

*“I find that I do general training and then I have to use my skills to interpret that into [occupational therapy]. There are so few courses that bring it all together.”*

One participant perceived this as an issue for this research to inform and for the College of Occupational Therapists to consider addressing.

### **Resources for training**

Despite this lack of specific courses, there are opportunities for relevant post-registration training and conferences that many consider essential for occupational therapists working in this area to attend if resources allow:

*“Ideally you would want to see everyone trained in AMPS, Sensory Integration, and certain key courses, but they are so expensive, you never meet that ideal.”*

Interestingly, the availability of resources and the degree of success in negotiating funding for such training is extremely variable across teams. Some describe having been successful in finding the funding for courses and feel they have benefitted from being line managed from within their learning disabilities teams with pooled budgets, rather than from within occupational therapy as under previous arrangements. For them, this has opened up wider potential sources of funding.

For many, however, a lack of resources limits access to training, with some occupational therapists referring to a constant struggle to get funding for essential courses, training budgets frozen and a blanket ban on paying for conference places. Within recently integrated teams with pooled budgets, some do find it more difficult to get on courses and describe this as possibly due to managers of joint teams not grasping the specialist nature of occupational therapists' skills. When people work for small services where there is a learning disability budget rather than an occupational therapy budget the chances of getting funding are reduced.

Some team managers encourage occupational therapists to attend generic rather than specialist training, potentially leading to erosion of occupational therapy skill. There is competition within the workforce due to limited resources.

### Distance from training

Occupational therapists in Scotland and Northern Ireland report particular problems with accessing good quality training and conferences, due to prohibitively high travel and overnight accommodation costs to attend courses in other parts of the country. They describe how some Scottish NHS Trusts have imposed a rule that courses outside of Scotland will not be funded.

### 3.8.3 Clinical and professional supervision

Occupational therapists working with people with learning disabilities attach importance to being able to access different types of supervision (clinical, professional and management) to maintain the quality of their practice. Their experiences of supervision differ, depending in part on how supervision itself is understood, as they say that their definitions of it are sometimes different from that of other professions in their teams. They recognise the importance of continuing professional development and perceive clinical and professional supervision as key to ensuring good practice. Some feel supported by well-structured formal supervision with additional informal support:

*"I enjoy supervision and think it's good for your [continuing professional development]."*

Whether or not there is a relevant person within occupational therapy to give clinical or professional supervision can depend on the size of the service. Lone occupational therapists in particular, or those without anyone of a more senior grade in their team, emphasise difficulties accessing supervision. Those at higher grades, for example lead and consultant occupational therapists, rely instead on peer support from those at a similar level in other teams.

Receiving clinical supervision from an occupational therapist who does not work with people with learning disabilities is found by some to be of limited value due to the lack of specific knowledge:

*"We did have an [allied health professional] lead that did do some professional supervision, but she never worked within learning disabilities. She was very useful for clinical reasoning, but not really around sort of [occupational therapy] specific issues."*

Some occupational therapists receive their clinical supervision from other professionals within their teams, such as a community nurse, or have developed reciprocal peer supervision arrangements. One focus group participant described how clinical supervision had been made possible by combining the services of two boroughs with a single manager working across both services. Another option is for clinical supervision to be bought in from outside the team, though some describe difficulty finding an appropriate person to do this.<sup>10</sup>

<sup>10</sup> The College of Occupational Therapists (2010) highlights the importance of occupational therapists accessing supervision from a professional who has a higher level of knowledge, skills and experience in the same field of practice.

### 3.8.4 Networking

Perhaps as a consequence of difficulties accessing formal post-registration training and clinical supervision, occupational therapists particularly value networking with each other. This encourages occupational therapists to look beyond their own service and supports them in developing the skills and knowledge they need to work with people with learning disabilities:

*“The more we share the more we move forward.”*

This seems particularly important when there is only one occupational therapist working within a team:

*“For many years, I was the only occupational therapist in the service and that was very hard . . . I thought I was doing okay until I got in touch with others.”*

Occupational therapists network through their locality groups, through the College of Occupational Therapists Specialist Section – People with Learning Disabilities and through taking advantage of technological advances (all discussed further below). They also describe utilising other development opportunities such as work shadowing, mentoring, supervision, and joint working with others:

*“working a case together . . . just asking somebody to come on a visit with you for another opinion”.*

#### Locality groups

The most mentioned form of networking and support in every country of the United Kingdom is participation in locality special interest groups. Some, though not all, of these groups are linked to the College of Occupational Therapists Specialist Section – People with Learning Disabilities. By meeting with their peers, anything from six-weekly to quarterly, occupational therapists share expertise and good practice, support each other and keep up to date with current developments:

*“We get together and talk about what we are doing . . . that’s the first rung up the evidence ladder.”*

*“In the past we’d all be working on little islands, but we are better now at coming together and using our resources better. . . .”*

Some groups are small, though others have up to 40 people attending. To occupational therapists working in isolation in particular, they are hugely valuable and reassuring.

#### College of Occupational Therapists Specialist Section – People with Learning Disabilities

Many occupational therapists working with people with learning disabilities are members of the COT Specialist Section and use it as a means of networking and developing their practice. They describe the value they place on, for example, regular contact through e mail and the quarterly newsletter. This is very much a ‘two-way process’ with information flowing from as well as to the members, and many of the locality groups feed into the National Executive Committee of the Specialist Section. One focus group participant particularly noted the ease of submitting an article or a book review to the newsletter.

Occupational therapists highlight the benefit they get from the responses the Specialist Section's National Executive Committee make to consultations and its input into guidelines for example about the occupational therapy role with people whose behaviour is challenging (COT 2009).

The Specialist Section's annual national conference is seen as a particular benefit, with one person stating:

*"Over the last 4–5 years, our specialist section conferences have been really good; there's been a lot of opportunity to share."*

Some occupational therapists also join other COT Specialist Sections, for example Housing and Work.

### **Using technological advances to improve practice**

Many occupational therapists describe using technological advances to share skills, experiences and resources and so improve their practice:

*"We share good practice so you're not reinventing the wheel . . . they're just templates and then we tweak them. It saves a lot of time."*

Information sharing has changed with the internet, as there is no longer a reliance on putting requests for information in occupational therapy publications and waiting for long periods of time for responses. Now e mail, e learning, video conferencing, and specialist networks such as the Sensory Integration Network are all available. Occupational therapists find it particularly positive to post and respond to queries on internet discussion forums and list servers (e.g. those run by the College and the MOHO Clearing House):

*"I recently sent a thing around the . . . network regarding the Canadian Model and there are five of us networking about it now."*

For some occupational therapists, the downside of using these tools is the time needed to use them effectively and getting into the routine of using them within their working day and having the confidence to upload information. Some do not find that the COT Specialist Section Discussion Forum is completely meeting their needs.

A suggestion from one of the focus group participants was that the Specialist Section could meet more of its members' needs by developing a well-maintained and moderated online library or resource repository, where ideas, templates and other resources can be shared between members:

*"A network where you can ask for ideas and it's there at your fingertips."*

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# 4 Limitations

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The authors hope that the findings of this research add usefully to the evidence base for occupational therapy with people with learning disabilities. They do however acknowledge certain limitations in its design.

For practical reasons, one of the researchers changed after the first phase of the study. Efforts were made to minimise any impact of this on the quality of the study, in particular the fact that the other researcher was involved throughout, from the inception of the study to its conclusion. It did, however, extend the length of the study, meaning that the data from phase 1 is approximately two years older than that of phases 2 and 3.

A particular limitation is the fact that many of the findings consist of what occupational therapists themselves say about their practice. The important perspective of people with learning disabilities themselves is missing and, among key stakeholders, only the views of support workers on practice have been included and these views could have been explored more fully.

A limitation of the focus group method used with the occupational therapists is that participants may have been influenced by peer pressure in their expression of some of their viewpoints. The researchers do not, however, feel that this has greatly influenced the findings, as the study was designed using eight separate focus groups and there was notable consistency of points made across the groups, with very few points being made in only one group.

The participants in this qualitative study all self-selected and it cannot be assumed that they are necessarily representative of all occupational therapists working with people with learning disabilities or all support workers, nor that these findings would be the same if different occupational therapists and support workers were interviewed. It was not, however, intended to seek findings that could be generalised, the aim being to explore and gain an understanding of an under-researched phenomenon that is occupational therapy with people with learning disabilities. It is felt that the findings add markedly to the understanding of practice in this area.

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# 5 Conclusion

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## 5.1 Summary of findings

This research set out to explore and document the nature of occupational therapy with people with learning disabilities across the United Kingdom, from the perspectives of occupational therapists and those paid to support people with learning disabilities. The findings from the study, as set out in this report, provide a rich and detailed description of occupational therapists' practice. The findings, presented under eight key themes, are of relevance to occupational therapists working in all settings, to people with learning disabilities themselves and to all those interested in the quality of their lives, including managers and commissioners.

Occupational therapists' passion for their **unique role** and their holistic, practical and creative work with people with learning disabilities has been described. They bring specific knowledge from their training, a key occupational perspective and a focus on meaningful activity, all of which impact on the quality of individuals' lives. This complements the perspectives of others in their multidisciplinary teams. A hands-on, adaptable and flexible approach, actually doing activity with people and creatively finding routes around barriers often helps move things forward for someone.

Particularly important to practice is underpinning theory such as occupational therapy practice models, the ability to analyse activity and a particular focus on the environmental factors that get in the way of someone doing what they want or need to do. Key to being able to work in a person-centred way seems to be developing relationships with people over time in order to support them to make informed decisions and to enable them to set their own goals. Occupational therapists are often involved with someone when their motivation to engage in activities is reduced, perhaps if they are occupationally deprived, or when others are struggling to find a way to engage them in activities.

The general purpose of **occupational therapists assessing people with learning disabilities** is to ascertain the impact of learning disabilities on occupational performance, that is how this affects someone's life and their engagement in the occupations that are important to them. These assessments are felt to add important objectivity to information gathering that might otherwise mean accepting at face value what others say about someone's abilities. Support workers seem particularly to value this independence of occupational therapy input.

Standardised occupational therapy assessments are sometimes used, though it can be difficult to identify tools that cover the wide range of abilities of people with learning disabilities, especially those with profound and multiple learning disabilities. Existing standardised assessments are therefore sometimes adapted and used in a non-standardised way in order for them to be more accessible.

These assessments, from their occupational perspective are often carried out through consensual direct observation in real environments and are described as leading to a real understanding of individuals' strengths and needs. This is the essential starting

point for designing, developing and purchasing effective support and services for people with learning disabilities. Recommendations regarding meeting these needs may relate to both the amount and the type of support needed, allowing, for example, a supported job or a residential placement to succeed by ensuring a better fit with the person. Information from occupational therapy assessments is therefore used by others to evidence the need for and design of support packages.

**Occupational therapy intervention with people with learning disabilities** was described, including the importance of intensive or long-term work due to this being a lifelong condition; with a complexity of needs that change over time. Many interventions involve an element of direct work with individuals to develop their skills, though the amount of involvement following assessment seems to vary enormously across teams.

Specialist knowledge from the breadth of occupational therapy training and core contributions regarding for example sensory needs, contribute to multidisciplinary support given to those with profound and multiple learning disabilities and those whose behaviour others find challenging.

The importance of working with individuals at times of transition is highlighted. Increasingly occupational therapists are supporting people with learning disabilities to gain work skills and paid or unpaid employment, or to carry out the role of being a parent.

Occupational therapists perceive **collaborative working with others to meet the needs of people with learning disabilities** as good practice. This includes working with other professions within their multidisciplinary teams, with people's families and support workers in various settings and with mainstream services. They describe having a consultancy role, providing recommendations for others to follow and a number of factors have been identified in the findings that influence whether these recommendations are carried out or not. Examples include whether the recommendations are achievable, the quality of the relationship with those who carry them out and the resources available to them. Occupational therapists often work with support workers to enable them to develop their skills. This may be either through informal support or through the provision of training, sometimes with other professions from their teams.

It has been established that developing a working partnership with those in mainstream health and social care services, for example other occupational therapy services, is important to ensure that the needs of people with learning disabilities are met. This may include jointly assessing whether it is the learning disability that is affecting someone's function or another factor.

The **outcomes of occupational therapy with people with learning disabilities** can be difficult to measure due to there being a limited number of tools that indicate change accurately. The perspective of the person with a learning disability, family carers and support workers on what the outcome should be and whether it has been achieved is particularly important, for example their satisfaction with their own occupational performance.

Various factors that influence the **recognition of occupational therapy with people with learning disabilities** were discussed, including the importance of evidence-based practice and increasing the limited amount of published research evidence to support practice. This could allow occupational therapists to provide a more consistent service

and strengthen their position in multidisciplinary teams. The importance of areas that occupational therapists focus on, such as meaningful activity, routines and the environment, is highlighted in key national documents, for example Department of Health (2009a) and Scottish Executive (2000). Assertively promoting a defined occupational therapy role seems important in ensuring that occupational therapy expertise is acknowledged and recognised in such documents.

**The impact of wider health and social care policy on occupational therapy with people with learning disabilities** was highlighted. The current financial climate impacts on both the resources available to fund support packages for individuals and the number of occupational therapists in post to provide specialist input in the areas described. Occupational therapists emphasise that a quality occupational therapy service that meets the needs of people with learning disabilities requires sufficient resourcing for there to be time to build rapport and get a true representation of the person through a thorough assessment. Many occupational therapists describe growing pressure to take on more generic roles, such as care management, though generally they do not feel this would be in the best interests of people with learning disabilities.

Occupational therapists describe changes related to eligibility and targets regarding waiting lists as creating a focus on quantity of referrals rather than quality of service and feel that the waiting list targets stem from an acute medical care model that is not appropriate for people with learning disabilities. These targets make long-term occupational therapy, such as sensory integration, difficult and seem to be leading to an increase in crisis response rather than preventative work, which sometimes results in more expensive support packages being required later.

Occupational therapists support people with learning disabilities in their right to access mainstream or generic health and social care services. Increasingly, they emphasise their wish to concentrate on a person's needs related to their learning disabilities and to promote inclusion into mainstream occupational therapy services for other needs. The extent to which provision of equipment to meet physical disability-related needs dominates caseloads today varies between teams. Some learning disability occupational therapists are still focusing on adaptations and equipment, which others are concerned leads to a risk of diluting the specialism and neglecting the broader aspects of the support needed by people with learning disabilities. Through persistence over time, however, many teams have had success in concentrating their role on specialist learning disability-related needs, recognising the expertise of other occupational therapists and supporting them around an individual's learning disability. Some have developed formal protocols with other health and social care occupational therapy services regarding respective roles.

The importance of occupational therapists **developing the necessary skills to work with people with learning disabilities** was highlighted. This is especially relevant with the focus on enabling access to mainstream services, as an occupational therapist will increasingly need skills to work with people with learning disabilities in whatever setting they are working in. There seems to be a need for development of pre-registration occupational therapy training to ensure that the content regarding learning disabilities is up to date and for more opportunities for students to have placements in learning disabilities teams during their training. More posts need to be created for newly qualified occupational therapists, thus allowing them to develop their skills and to become the experts of the future.

A need has been identified for the development of specialist post-registration training specific to both occupational therapy *and* people with learning disabilities, as well as more resources to allow occupational therapists to attend essential training on topics such as the AMPs and Sensory Integration. Many occupational therapists do stay up to date by taking opportunities to network with each other through their locality groups, through the College of Occupational Therapists Specialist Section – People with Learning Disabilities and through technological advances.

## 5.2 Recommendations

The following recommendations are made from the findings of this research (each cross-referenced to the appropriate section of this report).

### 5.2.1 Occupational therapists working in specialist learning disabilities teams need to:

- Work in close liaison with people with learning disabilities, support workers and family members and include them in all aspects of occupational therapy intervention from planning through to discharge. This includes ensuring that recommendations are achievable by all the relevant people (section 3.4.2).
- Develop a close working relationship with and provide consultation to mainstream health and social care occupational therapists to facilitate people with learning disabilities accessing their services. This includes developing formal local pathways or protocols setting out respective responsibilities (sections 3.4.3 and 3.7.3).
- Develop close working relationships with children’s occupational therapy services, alongside other disciplines, to facilitate a smooth transition for children with learning disabilities to adult services (section 3.3.6).
- Be confident and assertive and be able to use occupational language when appropriate (section 3.6.3) and consider developing marketing skills to sell your service (section 3.7.3).
- Continue to provide thorough, objective and independent assessments of the impact of someone’s learning disability on their occupational performance (section 3.2.2).
- Promote the value of occupational therapy with people with learning disabilities by developing and using measures that demonstrate the outcomes of interventions (section 3.5.2).
- Clearly articulate that meeting the needs of people with learning disabilities often requires remaining involved over a longer period of time and that short periods of intervention are often not sufficient to meet these needs (section 3.3.1).
- Develop evidence-based practice guidance and/or pathways demonstrating occupational therapy’s contribution to meeting the needs of particular groups of people with learning disabilities, such as those on the autistic spectrum, those with dementia, those whose behaviour challenges services and those with profound and multiple disabilities (section 3.6.1).
- Take opportunities to be involved in developing the evidence base by undertaking research into occupational therapy with people with learning disabilities (section 3.6.1).
- Contribute to the development of standardised assessments and outcome measures (sections 3.2.3 and 3.5.2).

- Offer more practice placements to occupational therapy students to ensure that as many as possible gain experience of working with people with learning disabilities during their training (section 3.8.1).
- Ensure occupational therapy representation on relevant learning disability and professional specific sub-groups and forums in employing organisations (section 3.6.3).
- Access supervision from a professional who has a higher level of knowledge, skills and experience in the same field of practice, whether this be clinical, managerial, educational or another type of work (section 3.8.3).

### **5.2.2 Those involved in occupational therapy education (either as lecturers in universities or as practice placement educators) need to:**

- Ensure that the content about people with learning disabilities in pre-registration occupational therapy courses is sufficient to ensure that students qualify as occupational therapists with the knowledge and skills necessary to work with people with learning disabilities in whatever setting they work in. This may include occupational therapists currently in practice and people with learning disabilities themselves being involved in teaching (section 3.8.1).
- Ensure that universities and occupational therapist practice placement educators work together to increase the number of student placements available that give students experience working with people with learning disabilities (section 3.8.1).
- Develop opportunities for post-registration training that is specific to the needs of occupational therapists working with people with learning disabilities (section 3.8.2).

### **5.2.3 The College of Occupational Therapists, the College of Occupational Therapists Specialist Section – People with Learning Disabilities and occupational therapists need to:**

- Disseminate the findings from this research and consider in particular how these findings can reach key stakeholders.
- Place an increased focus on influencing the direction of key government and other policy regarding people with learning disabilities to ensure that the value of occupational therapy is apparent (section 3.6.2).
- Consider how best to address occupational therapists' concerns about the shortage of occupational therapy posts in teams (section 3.7.2).
- Consider updating the College of Occupational Therapists Specialist Section – People with Learning Disabilities research and development strategy (COT and OTPLD 2003) and *Occupational therapy with people with learning disabilities principles for education and practice* (OTPLD 2003) in the light of the above research recommendations.
- Continue to take opportunities to network in varied ways with other occupational therapists working with people with learning disabilities, to ensure that knowledge and skills are developed and shared. In particular, to develop, contribute, share and disseminate resources (with the COT Specialist Section – People with Learning Disabilities) that individual occupational therapists have developed (section 3.8.4).

#### **5.2.4 Managers of occupational therapists working with people with learning disabilities need to:**

- Support occupational therapists' practice, and continuing professional development through the provision of necessary time and resources.
- Support occupational therapists to take into account the findings from this research, including in particular the provision of necessary time and resources.
- Support occupational therapists to undertake further research into occupational therapy with people with learning disabilities, as recommended below.
- Consider how best to address the shortage of occupational therapy posts within learning disabilities teams.

#### **5.2.5 Those involved in occupational therapy research need to:**

- Consider the research priorities identified in the College of Occupational Therapists Specialist Section – People with Learning Disabilities research and development strategy (COT and OTPLD 2003) and in the *Shaping our future* scoping and consultation exercise report (Williams et al 2008) when designing any research.
- Consider research regarding occupational therapy with people with learning disabilities in the following key areas:
  - Occupational therapy with people with learning disabilities from a wider perspective than what occupational therapists say about their own practice. This should include the perspectives of key stakeholders, including in particular people with learning disabilities themselves and their families.
  - The effectiveness of specific occupational therapy interventions and outcome measures that can demonstrate this.
  - Standardised occupational therapy assessments that better meet the needs of and are accessible to people with learning disabilities. This may include:
    - research into the development of new or adaptation of existing assessments to better meet their needs;
    - research to enable a consensus to be reached about which adaptations can be made to currently used standardised assessments (such as the AMPS) without compromising standardisation of the assessments.
  - The impact of eligibility criteria and targets regarding waiting times on the quality of the interventions of occupational therapists (and others in community teams) with people with learning disabilities.
  - How students and newly qualified occupational therapists can best be enabled to develop the necessary skills to work with people with learning disabilities.
  - How occupational therapists can best support people with learning disabilities to gain employment.
  - The views of occupational therapists in mainstream services regarding how people with learning disabilities can best be enabled to access their services.
  - How best to address the shortage of occupational therapy posts within the learning disability field.

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# Appendices

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## Appendix 1: Methods

The research was carried out in three consecutive phases all of which received ethical approval from the College of Occupational Therapists and the NHS National Research Ethics Service. The study was monitored by a Steering Committee consisting of the researchers, the Chair of the College of Occupational Therapists Specialist Section – People with Learning Disabilities (and members of the Professional Practice and Research and Development staff of the College of Occupational Therapists). It was monitored by the College via quarterly reports to its Specialist Section Clinical Forum.

### Phase 1

The first phase audited the extent to which occupational therapists working with people with learning disabilities across the United Kingdom are meeting the standards of practice described in OTPLD (2003), using a 13-page questionnaire. In addition to asking for demographic data about respondents' length of experience and employment details, this sought specific information about practice by asking for information about occupational therapy interventions undertaken with three people with learning disabilities. The questionnaire was piloted on ten members of the COT Specialist Section – People with Learning Disabilities National Executive Committee and minor amendments made to its structure and layout as a result of their feedback.

In an attempt to target as representative a sample of occupational therapists as possible, both members of the COT Specialist Section – Learning Disabilities and non-members were included in the sampling frame. Three hundred and nine individuals were identified and the project budget and timescale allowed for approximately half of these individuals to be surveyed. As a consequence 150 individuals were randomly selected from this list and were sent a letter of introduction, the questionnaire, and a stamped addressed envelope. They were given one month to complete and return the questionnaire.

Sixty-nine of the 150 questionnaires were returned completed, representing a response rate of 46%. This represents an improvement on the expected average response rate of 30–40% for a postal survey of this type (Barnard and Seale 1998).

### Phase 2

Having established in what ways standards of practice were being met, the second phase aimed to explore the nature of occupational therapy with people with learning disabilities and to identify examples of good (and new) practice. The views of occupational therapists working with adults with learning disabilities were sought using eight separate focus groups across the United Kingdom. Focus groups were selected in preference to other qualitative data collection methods because (as described by Krueger and Casey 2000), they were thought to:

- provide a forum in which participants with similar experiences could meet and explore their understanding of their practice in their own way and using their own words;

- enable the group facilitator to establish a rapport with a range of participants in a relatively quick and easy way; and
- enable the participants to build upon one another's responses and thereby generate ideas they may not have thought of in a one-to-one interview.

Individual occupational therapists currently working with people with learning disabilities responded to requests for volunteers to take part. Those expressing an interest were e mailed a participant information sheet and consent form and asked to complete and return the latter if they wished to be involved. It was anticipated that up to eight individuals would take part in each group and in the event a total of 49 occupational therapists participated. The location of the eight focus groups was determined by a commitment to have at least one group in each country and the geographical spread of volunteers. In the event they took place in Cardiff, Belfast, Edinburgh, Exeter, London (two groups), Manchester and Southampton.

Initially a pilot group was run, following which changes were made to the structure of the questions, to ensure that relevant data was gathered. Each focus group was facilitated by the same person in accordance with a focus group schedule comprising topics of conversation to guide the discussion. Following introductions the purpose and format of the group were reiterated to participants and reassurances about anonymity and confidentiality made. The topics covered were influenced by the findings of phase 1 and broadly sought to:

- identify specific occupational therapy skills in the learning disability field and occupational therapists' unique contribution to people with learning disabilities;
- explore occupational therapists' opinions on good practice including what constitutes a good outcome (this included identifying and discussing examples from people's own practice);
- identify barriers to good practice;
- explore directions for the future of occupational therapy practice when working with people with learning disabilities including views on what is cutting edge practice.

Participants were encouraged to talk freely about the topic under investigation, with the facilitator keeping contributions to a minimum, only interjecting to summarise what had been said, seek the opinion of any non-contributing members or move the conversation on. Each focus group was audio-taped and ran for no more than one and a half hours.

### **Phase 3**

The research aimed to explore occupational therapy with people with learning disabilities from the perspective of support workers as well as occupational therapists themselves. The important role of the occupational therapist as a consultant making recommendations for others, such as support workers to follow, is evident in the literature (see for example Donati 2009) and this was immediately apparent during phase 2 of the study. The third phase therefore sought the views of support workers, as an example of a key stakeholder group in occupational therapy with people with learning disabilities.

Telephone interviews were thought to provide a confidential, practical and relatively cost effective method (from both the support workers' and the researchers' perspectives) to gather qualitative data. Those paid to support people with a learning

disability (for example residential support, outreach, or day centre workers) were invited to participate, if anyone they supported had over the preceding year received intervention from an occupational therapist based in a community learning disability team. Volunteers were sought by publicising the project on the Learning Disability Health Network e mail distribution list and by distributing flyers to Community Teams for People with Learning Disabilities and support providers across the country. The researchers intended to interview ten support workers, to generate the breadth and depth of information about their perceptions of occupational therapy interventions while still being a manageable number. In the event, however and despite extensive efforts to find participants, only five support workers volunteered and were available to be interviewed within the three month timescale available to complete this phase.

Volunteers were sent a participant information sheet and consent form and were asked to return the latter to confirm their continued willingness to be involved. Contact was made with them to explain the interview process and to arrange a convenient time for the interview to take place. Each interview then followed a semi-structured format (informed by the analysis of data from the first two phases) and lasted up to half an hour. The participants were encouraged to talk freely about the topic under investigation, the researcher mainly interjecting to summarise and clarify what had been said and move the conversation on. Interviews were audio-recorded with the prior consent of participants.

### **Analysis of data from focus groups and telephone interviews**

The focus groups and telephone interviews were transcribed in full and a thematic analysis was then carried out by the researchers, using the methods described by Marks and Yardley (2004) and the six phase process described by Braun and Clarke (2006). As this is an under-researched area, the intention of this analysis was to achieve a rich overall thematic description of the entire data set and a sense of the predominant or important themes. Whether or not something 'counted' as a theme was determined not merely on prevalence, but rather on whether it captured something important in relation to the overall research aims and objectives, as suggested by Braun and Clarke (2006). Both manifest and latent themes identified in the transcripts were coded and the analysis was carried out inductively. NVivo 8 computer assisted qualitative data analysis software was used to facilitate the carrying out of this thematic analysis (QSR International 2008).

In developing a coding frame, patterns in the data were labelled with codes and distinctions drawn by organisation of content into a set of multiple categories. Low level codes were used initially at the initial textual level, though these were integrated into more powerful conceptual categories by means of splicing (whereby codes were grouped together or merged) and linking (whereby patterns of association between themes were identified and links or clusters created to indicate conceptual relatedness of themes). The coding categories in the final coding frame formed a hierarchy, with higher level categories progressively sub-divided into lower level sub-categories. Each code had a label, an operationalisation of the concerns of the theme and an example of a chunk of text that should be coded as fitting into this category. The researchers created and used mind maps of each individual theme to support the exploration of them and to allow deeper analysis and understanding of the data.

This study was carried out by researchers who are themselves occupational therapists experienced in working with people with learning disabilities and who therefore did not approach the data in a 'vacuum' (Braun and Clarke 2006). The risk of bias when investigating the work of clinicians in that same field is therefore acknowledged. In an

attempt to increase the trustworthiness of the analysis and in particular its dependability (Taylor 2007), more than one analyst was involved as recommended by Pope et al (2006). Both researchers analysed the whole data set and four other members of the National Executive Committee of the COT Specialist Section – People with Learning Disabilities were also involved with the initial stages of analysis of each of the focus group transcripts.

## Appendix 2: Tables

Data from the questionnaires completed by 69 occupational therapists during phase 1 of this research is referred to in section 3 of this report and appears in the tables below.

**Table 1** How many years of experience have you had working with people with learning disabilities?

Number of years	No. of respondents (total 69)	%
20 years plus	11	16
16–20 years	10	14
11–15 years	16	24
6–10 years	13	19
3–5 years	10	14
0–2 year	9	13

**Table 2** Main reason for referral

Reason	No. of cases (total 207)	%
Assessment of activity of daily living skills	151	73
Aids and equipment provision	54	26
Risk assessment	53	25
Re-housing	36	17
Leisure needs	36	17
Mobility issues	33	16
Eating and drinking	30	14
Sensory processing/integration	29	13
Moving and handling issues	25	12
Seating and wheelchairs	23	11
Travel training	21	10
Health promotion	20	9
Communication issues	19	8
Social skills training	14	7
Employment needs	12	6
Hand function	9	4
Parenting	9	4

*Continued overleaf*

**Table 2** *Continued*

<b>Reason</b>	<b>No. of cases (total 207)</b>	<b>%</b>
Educational needs	8	3
Transition from child to adult services	7	3
Assistive technology provision	6	2
Specialist housing design	6	2
<b>Other</b>		
Development of independent living skills	6	2
Dementia issues	3	1
Budgeting and transactions issues	3	1
Mental health issues	3	1
Engagement in purposeful activity	3	1

**Table 3** Which sort of assessment did you undertake with your service user?

<b>Assessment type</b>	<b>No. of cases (total 207)</b>	<b>%</b>
A non-standardised assessment (e.g. department devised checklist)	120	58
A standardised assessment (i.e. AMPS, MOHOST, COPM)	19	9
Both of the above	41	20

**Table 4** Which (if any) of the following occupational therapy colleagues have you consulted in the course of your work in the learning disabilities field in the past two years?

<b>Colleagues from</b>	<b>No. of respondents (total 69)</b>	<b>%</b>
Social service	65	94
Physical rehabilitation (hospital)	41	59
Mental health	37	54
Paediatric	32	46
Elderly care	15	22
Wheelchair service	2	3
Other (responses included special dementia service, local housing, special school, assistive technology and children service)	6	9

**Table 5** Did you have any involvement with any mainstream services during the course of this case?

Answer	No. of cases (total 207)	%
Yes	118	57
No	77	37
<b>Of those who answered 'yes', contact was with the following mainstream services</b>		
Community nurses (type unspecified)	24	12
Social service occupational therapy department	22	11
Social work department	14	7
Physiotherapy department	12	6
Further education staff	11	5
Care manager	11	5
Speech and language therapist	10	4
Disability employment service	10	4
Day services	10	4
Local authority housing department	10	4
Leisure centre	8	3
GP/practice nurse	7	3
Advocacy service	7	3
Wheelchair service	6	2
Voluntary agency (not specified)	5	2
Psychologist	5	2
Charitable organisation (not specified)	5	2
Special school	5	2
Dietician	5	2
Hospital consultant/nursing staff	4	1
District nurse	3	1
Hospital-based physical rehab occupational therapist	3	1
Child protection service	3	1
Specialist equipment company	3	1
Moving and handling adviser	2	< 1
Health visitor	2	< 1
Dentist	2	< 1

*Continued overleaf*

**Table 5** *Continued*

Contact was with the following mainstream services	No. of cases (total 207)	%
Nursing home staff	2	< 1
Residential care staff	2	< 1
Epilepsy nurse	2	< 1
Bank for financial advice	2	< 1
Midwife	2	< 1
Police	2	< 1

**Table 6** Did you feel that you met the aims of your occupational therapy intervention with the service user?

Answer	No. of cases (total 207)	%
Yes	149	71
No	44	21
Not answered	14	7

**Table 7** Who or what do you think is going to be the focus of occupational therapy intervention in the learning disabilities field in the future?

Focus of occupational therapy intervention	No. of respondents (total 69)	%
School leavers/transition between child and adult services	27	39
Parents with learning disabilities	25	36
Supported/open employment	23	33
People with profound and multiple learning disabilities	22	32
Older people with learning disabilities	20	29
Dementia	19	27
Mental health issues	10	14
Moving to more independent living	10	14
Challenging behaviour	9	13
Sensory processing/integration	9	13
Elderly carers and service users moving from family homes into supported housing	7	10
Re-housing and specialist housing design	6	9

**Table 7** *Continued*

<b>Focus of occupational therapy intervention</b>	<b>No. of respondents (total 69)</b>	<b>%</b>
Health promotion Issues	5	7
Staff training	5	7
Autistic spectrum disorders	5	7
Liaison with mainstream services	5	7
Facilitating leisure/community opportunities	4	6
Equipment and adaptations	4	6
The development of specific assessments	2	3
Forensic issues and offending behaviour	2	3

**Table 8** What would help inform your practice about this particular area or client group?

<b>Respondents asked for more research, information and/ or training in the following areas:</b>	<b>No. of respondents</b>	<b>%</b>
Sensory processing/integration	17	25
Parents with a learning disability	14	20
Use of specific assessments (such as AMPS, MOHO, COPM)	11	16
Mental health issues (i.e. those with dual diagnosis)	6	9
Postural management	6	9
Older adults with learning disabilities	5	7
Dementia	5	7
Autistic spectrum disorders	4	6
Transition	4	6
Other	17	24







# Occupational therapy and people with learning disabilities

## *Findings from a research study*

Occupational therapists work with people to promote health, prevent disability and develop or maintain abilities (COT 2009). Within the area of learning disabilities occupational therapists have a wide variety of roles enabling people with learning disabilities to engage in occupation and promote their independence and community participation.

They bring a unique understanding of the importance of engagement in occupation and are passionate about their person-centred and practical role, which focuses on independence and requires them to be adaptable, flexible and creative problem-solvers.

This research was commissioned by the College of Occupational Therapists and its Specialist Section – People with Learning Disabilities, with the aim of exploring and documenting the nature of occupational therapy practice with people with learning disabilities across the United Kingdom, from the perspectives of occupational therapists and support workers. This report outlines the findings and makes recommendations.

This publication aims to:

- Provide a comprehensive overview of the nature of occupational therapy practice for people with learning disabilities in the UK.
- Inform, guide and support occupational therapy practice across the UK.
- Drive forward best practice in the field of learning disabilities, raising the profile of occupational therapy practice for the profession.
- Make recommendations for all occupational therapists, managers, commissioners, and to be helpful for carers, their families and others who work in the field of learning disabilities.

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Alison worked as a Clinical Specialist Occupational Therapist within both a community learning disability team and a specialist in-patient service until 2009 where she developed her particular interest in the specialist role of occupational therapists within these teams.

Alison is currently a Practitioner Researcher for the Collaborations for Leadership in Applied Health Research and Care (NIHR CLAHRC) for Cambridgeshire and Peterborough where she continues to combine her interests in research and clinical practice.

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David has had a particular interest in the occupational wellbeing of people with learning disabilities since first working as a support worker nearly twenty years ago. He has worked as an occupational therapist in community learning disability teams in Sussex, Surrey and London.

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