

CONSULTATION QUESTIONS

Progress and Challenges

Q.1 Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/carer?

Yes No

Please provide any comments, evidence and/or examples here

The College of Occupational Therapists is delighted to provide a response to this consultation. The College is the professional body for occupational therapists and represents over 28,000 occupational therapists, support workers and students from across the United Kingdom. Occupational therapists work in the NHS, Local Authority social care services, housing, schools, prisons, voluntary and independent sectors, and vocational and employment rehabilitation services.

Occupational therapists are regulated by the Health and Care Professions Council, and work with people of all ages with a wide range of occupational problems resulting from physical, mental, social or developmental difficulties.

The philosophy of occupational therapy is founded on the concept that occupation is essential to human existence and good health and wellbeing. Occupation includes all the things that people do or participate in. For example, caring for themselves and others, working, learning, playing and interacting with others. Being deprived of or having limited access to occupation can affect physical and psychological health.

The findings of the evaluation broadly reflect the College's views about services for people with learning disabilities. In addition to the evaluation carried out by the Scottish Government, the College and its Specialist Section –People with Learning Disabilities released the findings of a research report that considered how people with learning disabilities are supported by occupational therapists (Lilywhite and Haines 2010). This report which included results from Scotland has identified some additional problem areas that are highlighted in Q3.

In addition, the research report indicates that despite the principles in *The Same as You?* focusing on improving everyday lives and independence, after ten years occupational therapists still feel that their role is not recognised and there is a shortage of occupational therapy posts. Approaches that occupational therapists may use such as sensory integration (which focuses on adapting the environment to accommodate sensory needs which reduces challenging behaviour and enhances everyday living skills) are neglected. Occupational therapists in Scotland feel that the waiting lists targets in learning disability services have been derived from acute, medical models do not benefit people with learning disabilities. Due to waiting list pressures the occupational therapists have to discharge people early with unmet needs and have less time to focus on skill development. This does not ultimately deliver the best services for people with learning disabilities or their families and carers.

Lilywhite A, Haines D (2010) *Occupational therapy and people with learning disabilities. Findings from a research study*. London: COT.

Available at:

www.cot.co.uk/library-publications/cot-publications/a-z-listing?page=lq

Q. 2 Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of *The same as you?*

Please provide any comments and/or examples here

The College felt that *The Same as You?* set the right direction with a human rights approach that highlighted the right to have an everyday life with everyday opportunities. Despite the problems identified in Q1 and Q3, occupational therapists have worked directly to support people with learning disabilities to achieve the goals that are important to them such as living in their own homes, have friends and being in employment.

Occupational therapists describe the passion they bring to this work and how the occupational therapy training in both physical and mental health enables them to work well in this complex area (Lilywhite and Haines 2010). When able to, the occupational therapists can focus on occupation and enabling independence. They describe their approach as practical, adaptable and persistent using a person centred focus (Lilywhite and Haines 2010).

In addition to the policy focus on everyday life, the College think that that the closure of the long stay hospitals and increasing profile of autism have been great achievements in the past 10 years.

Q. 3 Can you give examples of issues in current work and/or policies that still need to be addressed?

Please provide any comments and/or examples here

Occupational therapists have highlighted several problems areas in the published research report (Lilywhite and Haines 2010). They identify that in the past few years services seem to be moving away from the policy emphasis on having an everyday life. Instead services increasingly emphasise crisis response rather than prevention.

An increased demand for occupational therapy assessments has reduced the ability to offer long term interventions that would usually aim to develop the skills for independent living.

Occupational therapists report being under increasing pressure to change recommendations in reports due to funding implications. Occupational therapists value their ability to provide independent, objective assessments of a person's level of skill and support needs but at times feel pressured to change their findings because of costs.

The College would also like to add a concern based on the interim findings of the Winterbourne Review which is how to ensure professional expertise gets to the front line support workers. Occupational therapists know that having support workers who are engaged and able to follow recommendations is crucial and have focused on developing their relationships with this group as it improves outcomes for people with learning disabilities (Lilywhite and Haines 2010). The Winterbourne Review demonstrates what can go wrong if support staff are not supported to provide excellent care and rehabilitation.

Q. 4 Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?

Please provide any comments and/or examples here

The College and its Specialist Section- People with Learning Disabilities have had several work strands to improve services:

- Project to improve access for people with learning disabilities to generic occupational therapy health and social care services. This has included published material and training sessions for mainstream occupational therapists to better understand what their responsibilities are and how to work with people with learning disabilities. This has also involved encouraging specialist occupational therapists who work in learning disability services to support mainstream colleagues and develop protocols to support joint working.
- Release of the research report "*Occupational therapy and people with learning disabilities*" (Lily white and Haines 2010) which included recommendations for improving practice. The recommendations have targeted areas such as the increased use of standardised outcomes measures to better demonstrate improvements and change. An audit tool has been produced so occupational therapists can audit their practice against the research recommendations.
- Contribution to the Winterbourne Review and pledging to improve practice in this area by contributing to the refresh of the document "*Challenging Behaviour -A unified Approach*" (RCP/BPS/RCSLT 2007)
- COT Specialist Section –People with Learning Disabilities has an active group in Scotland who have run study days and events over the past ten years where occupational therapists have been able to share best practice and develop specialist skills.

Good Practice - Individuals

Q.5 What have you done, as an individual, to make positive changes within your local area?

Please provide any comments and/or examples here

N/A

Future Priorities - Healthcare

Q.6 What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?

Please provide any comments and/or examples here

The College believe that further work is required to help mainstream health staff understand how to make reasonable adjustments to their services to ensure they are accessible for people with learning disabilities. There is still a lack of understanding about how to make such adjustments to service delivery. Some acute general hospitals have piloted having a specialist learning disability professional such as a nurse or occupational therapist employed within the hospital who supports teams to make reasonable adjustments. This has resulted in better health outcomes for people with learning disabilities and improved satisfaction for family carers.

Ensuring people with learning disabilities have access to meaningful activity and occupation is a vital way to enhance their health and wellbeing. Occupational therapists have skills in breaking activities down into their constitute parts so they can be adapted to suit an individual's participation level and skill development required. They can also teach these skills to support staff to increase participation in meaningful everyday activity. The College would like to see more recognition of the occupational therapy role in this area.

Future Priorities - Education

Q.7 What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?

Please provide any comments and/or examples here

Occupational therapists have reported that local colleges in Scotland are struggling to cope with cutbacks and have difficulty dealing with students with learning disabilities and challenging behaviour which was not addressed in school life. Occupational therapists have been working to help local colleges to address this in two ways and would like to see more of these occupational therapy led initiatives:

- By going into colleges with other allied health professions and nurses to talk to teaching staff about how students with mild learning disabilities may present and how to support these students. This has had positive results, empowering teaching staff and meaning students with mild learning disabilities get a better service to meet their needs.
- By working with tutors to co-facilitate learning in individual sessions to help for example, reduce challenging behaviour and increase participation in learning.

Future Priorities – Independent Living

Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?

Please provide any comments and/or examples here

The College believe that people with learning disabilities need a genuine choice of independent living options. For some people the desired option will be to live in their own home but others may prefer to live with a small group of people. The College would like to see assurances that people are given choice about where and

with whom they live.

In addition, independent living requires the development of independent living skills which occupational therapists are able to facilitate. Some occupational therapists report that time for skill development has been eroded and that this work is no longer viewed as critical to learning disability services. Ultimately this is not a cost effective approach because the more a person is able to do for themselves, the smaller and less expensive the care package that is required.

To fully embrace the development of independent living skills will require a shift in approach for some services which who still disempower people with learning disabilities by not allowing them to engage in everyday activity. More positive risk taking should be encouraged to allow people with learning disabilities to live as independently as possible. Occupational therapists should be an integral part of the drive for independent living.

Future Priorities – Employment

Q.9 What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?

Please provide any comments and/or examples here

The College believes that a range of options for employment opportunities is required for people with learning disabilities to match skill level and ability. Occupational therapists report that some of the current organisations who place people with learning disabilities in employment, offer minimal support afterwards which can exacerbate breakdown of employment. Occupational therapists are experts at matching people's ability to work demands. They can improve work skills in the individual but can also adapt working environments and tasks so the individual can be meaningfully employed.

Future Priorities

Q.10 What other future priorities do we need to focus on? (Please list these in order of importance with the most important first)

Please provide any comments and/or examples here

The College believe the following areas should be future priorities:

- Improving housing stock for people with learning disabilities. As independent living skills improve there is a need for appropriate housing for people to move into and occupational therapists report that there are problems finding such housing.
- Improving integrated working between healthcare, education, housing and employment. More integrated systems would allow the right expertise to be accessed in time before problems escalate and turn into expensive crises.

- **Improved services for women with learning disabilities who are pregnant/early parents.** Occupational therapists are receiving increasing referrals for expectant mothers well after 20 weeks of pregnancy or new mothers who are assessed for their parenting skills. While child protection has to remain the key driver, the women can find the process very distressing and particularly feel they are left without support if a child is removed from them.
- **Improved IT and data collection systems.** Accurate information about people with learning disabilities is difficult to obtain. Occupational therapists report feeling frustrated at systems that cannot process speciality assessment results and outcome measures meaning it is difficult to collate larger data sets to derive for example, information about cost effectiveness.