# **Leading fulfilled lives**

Occupational therapy supporting people with learning disabilities

 Royal College of Decupational Therapy

 Constrained Therapy

 Therapists

## Leading fulfilled lives Occupational therapy supporting people with learning disabilities

The right of all people, regardless of their abilities, to have opportunities to participate in a full range of everyday activities (occupations) within their community is recognised by the United Nations.<sup>1</sup> This right underpins the whole concept of occupational therapy philosophy and practice.

People with learning disabilities face particular challenges in fulfilling this expectation, whether developing social relationships<sup>ii</sup>, gaining paid employment<sup>iii</sup> or taking part in their communities. To help them manage a range of situations, occupational therapists tailor and adapt their approach to support people with learning disabilities to:

- Lead fulfilled lives by developing skills for daily living, accessing education, work and taking part in family and cultural life, leisure and sport.
- Transition through the key stages in a life course – for example, from childhood to adulthood, moving from residential care to community support, ageing and end of life.

In order for people with learning disabilities to have a good quality of life and for services to be able to meet demand, there needs to be more focus on early intervention, prevention and management, at a universal, targeted and specialist level of health and social care.

By 2030, the life expectancy for people with a learning disability is projected to increase by 164% to 80 years of age<sup>iv</sup>. Medical advances and measures to tackle discrimination have led to life expectancy catching up with the general population, but this increase means more people living with multi-morbidities.<sup>v</sup>

The Royal College of Occupational Therapists (RCOT) argues that to ensure people can live well with complex morbidities, service provision must be reshaped in order to optimise multidisciplinary working. This action is given a further sense of urgency with the reported 40% drop since 2010 in specialist learning disabilities nurses<sup>vi</sup> and fewer pre-registration nursing students<sup>vii</sup>. This means commissioning services to:

- Centre on supporting people to access and participate in education, work and mainstream community resources.
- Clear access points for mainstream services to specialist expertise and guidance.
- Create strong working partnerships across sectors to ensure people with learning disabilities are able to maintain their health and wellbeing through healthy occupations.

## **Capitalising** on the occupational therapy workforce

Occupational therapists work with people to develop an all-round understanding of their skills and abilities to perform daily activities (occupations) in the home, at school, in work or in the community.

Occupations involve the integration and use of sensory, motor, cognitive, perceptual, emotional and social skills and abilities. By assessing these skills and examining where the person will be functioning (for example, their home, school or workplace), occupational therapists can help people develop skills, modify the activity or the environment to create the best person/environment/occupation fit. Put simply, the best outcome for the person.

This report makes recommendations for effective use of the occupational therapy workforce in order to enhance the life opportunities for people with learning disabilities.

## **Recommendations** – Services should deploy occupational therapy expertise to:

- 1. Ensure participation within communities is a core activity in service commissioning and delivery.
- **2.** Support people with learning disabilities to live fully integrated lives within communities.
- **3.** Create packages of care and support to enable people to get the right care in the right place.

#### Universal service example: Sport for Confidence

Sport for Confidence supports people with learning disabilities to access opportunities to engage in an inclusive sport and physical activity programme. The model involves an occupational therapist and a specialist sports coach working in a leisure centre. The occupational therapist advises on adapting and grading the activities and programme for adults with learning disabilities and works closely with the leisure centre staff, coaches and community learning disabilities teams.

**Impact:** 50 groups per week over eight locations. Over 300 people a week are being offered a choice of 15 different sports and activities. People with learning disabilities can access different programmes ranging from fully supported, therapy-led groups to mainstream activities.

## All people with learning disabilities can participate in healthy occupations

#### Ensure participation within communities is a core activity in service commissioning and delivery.

Recent legislation, such as the Care Act in England<sup>viii</sup> and Social Services and Wellbeing Act (Wales)<sup>ix</sup>, has directed care and support services to listen to and understand the needs of people with learning disabilities and to work with them to achieve their own wellbeing outcomes. Further initiatives such as the 'stopping over-medication of people with a learning disability, autism or both with psychotropic medicines' (STOMP) campaign support the move away from a medicalised model of care<sup>x</sup>. It is widely recognised, however, that there is a need for on-going work, in particular supporting access to employment and lifelong learning, improving access to health services and integration into local communities.

A fundamental principle of occupational therapy is to enable participation in society. Key occupations for participation are, among others, education, employment, sports and leisure.

#### The difference occupational therapy makes:

As well as working with individuals, occupational therapists can support community integration by advising and training families, care providers, community and education providers and employers.

Occupational therapists understand the changing interaction between the person and their environment, and utilising their skills will help to ensure communities are more inclusive and sensitive to everyone's needs.

## Key components for delivering the recommendation

#### Position occupational therapists to:

- Develop wider partnerships to create access to opportunities in education, work and leisure.
- Provide advice and training to families and service providers.
- Create clear access points for partners and service providers to utilise advice and guidance from occupational therapists.

## Fatima and Jamila's Story

Sisters Fatima and Jamila moved with their family to the UK at the age of 12 and were not known to services. They were referred to occupational therapy by their GP as they were not attending college and withdrawing from family life. The sisters wanted to be seen by the occupational therapist together. The assessment led to:

Accessing the community. For opportunities to mix with other people, the sisters decided they would like to attend an art class and the gym. The occupational therapist supported them to attend an annual health check at their GP's and advocated for Gym on prescription as the GP had not identified physical fitness as a priority. A benefits application was made to fund these activities, as well as a bus pass.

**Safeguarding.** The occupational therapist identified concerns over potential radicalisation through internet use and made referrals for Safeguarding and the National Crime Agency Prevent programme. Working jointly alongside the local Police Prevent Team risks were identified.

Concerns were raised over the sisters' behaviour at College resulting in their exclusion. The occupational therapist worked alongside the local Police Prevent team and college tutors to support their re-engagement at college.

Fatima and Jamila also disclosed information suggesting on-line sextortion, posting of pornographic material and stalking. The occupational therapist supported them to report this to the Police and consequently the Porn Hotline.

Advice and guidance. The occupational therapist provided advice and information to the police on how to make their training accessible to people with learning disabilities so that the twins could be taught how to stay safe online.

#### IMPACT

With support in place Fatima and Jamila are attending a College course, going to the gym and swimming sessions on a weekly basis, and their social media activity has reduced. They are seeing a psychologist for help to manage anger and the Prevent team are no longer involved.

## Occupational | Improving Lives Therapy | Saving Money

# **People** with learning disabilities are supported to manage changes throughout life

Support people with learning disabilities to live fully integrated lives within communities.

Being and taking part in the community should happen throughout a person's life. Their role, and what they do in the community, will vary depending on the stage of a person's life and their interests. For example, integrating a child or young person into the community may focus on home, school, and leisure, while integrating an adult into the community may focus on home management, employment, leisure, and social or religious activities.

There are key stages in the life of someone with a learning disability where significant adjustment might be needed, and this may involve professional help. These stages include the transition from childhood to adulthood, the death or ill health of a carer, and ageing.

#### The difference occupational therapy makes:

Occupational therapists review peoples' aspirations, abilities and needs at key points of transition throughout their life. A stepped approach provides:

- one off advice and guidance;
- targeted training to care staff and families;
- a tailored one to one approach for people with more complex needs or situation.

Occupational therapy expertise needs to be available and accessible across sectors and delivered in the relevant environment. For example: in school or higher education institutes, through vocational support services, in sports and leisure centres or older people's extra care housing or care homes.

**Alistair's story** demonstrates the effectiveness of occupational therapy in helping a person with learning disabilities achieve their chosen goals and reach their full potential.



View the film here https:// bit.ly/2WV mmF5

## Tracey's Story

Tracey is 62 with a global learning disability. Tracey lived with her mother, did not attend school and was cared for like a child. When Tracey's mother died she moved in with her aunt. She continued to live a very sheltered and dependent life. When the aunt died her son inherited responsibility for Tracey.

**Managing risk.** A referral was made to the Learning Disabilities Service to help manage a very vulnerable and potential safeguarding situation. The family felt Tracey should be in care or have 24-hour support in a home of her own. The cost of a 24-hour support care package was calculated at **£1,354** per week, which equates to an annual cost to the Local Authority of **£70,408**.

**Taking an assets based approach.** An occupational therapy assessment was completed and the occupational therapist recommended two days at the local authority centre with an individualised care plan to prompt independence and 21 hours per week to support with reading letters, paying bills and shopping. Tracey moved into a warden assisted bungalow and a graded treatment plan was delivered by the occupational therapist.

### IMPACT

Tracey learnt the skills to look after herself and her home independently. Road safety/travel training and the local learning centre supported Tracey to gain paid employment in a kitchen for five hours per week and travel there independently.

#### Saving money for the public purse

The cost of occupational therapy involvement was **£516** (12 hours at £43 per hour). Housing and the care plan costs **£33,436** per annum saving the Local Authority **£36,972** each year.

## Key components for delivering the recommendation are to:

- Take an assets based approach.
- Balance risk and choice taking into account the meaning and value of the occupation to the person when assessing risk.
- Keep people with learning disabilities connected with their communities, family and friends.

## Occupational | Improving Lives Therapy | Saving Money

## **People** with complex needs and behaviours are supported close to home

#### Create packages of care and support to enable people to get the right care in the right place.

Research shows that people living in residential institutions experience occupational deprivation (a lack of meaningful occupations and routine).<sup>xi</sup> Understanding the impact of this deprivation is important when considering people's behaviours, particularly if these are challenging.

Approximately 1,827 people in the UK are inpatients in learning disability units.<sup>xii, xiii, xiv, xv</sup> Each country has targets to reduce the number of inpatient beds and provide more support in local communities.

#### The difference occupational therapy makes:

Occupational therapists assess a person's needs and advise on activities they can do that will improve and support their wellbeing. They identify a range of activities for the person to take part in, and encourage them. This is a tailored, personalised approach<sup>xvi</sup> that can lead people, as well as their family and their care staff, to learn new skills and find what's right for them.

In addition, occupational therapists recommend what type of support is needed, how best to work with the person, how to prompt and encourage, or how to set up the environment around them.

For people with complex behaviours, occupational therapists can advise on the therapeutic use of activities to help regulate emotions. Adopting therapeutic activities as part of an overall package of strategies can reduce the need for psychotropic medication.

## Key components for delivering the recommendation:

#### Use occupational therapists:

- as an alternative or as part of a positive behaviour support approach to cater for people's needs.
- to train and advise formal carers to take up a personalised approach to care.
- to identify suitable housing and support.

## lan's Story

lan had served a prison term and was living in a specialist forensic rehabilitation unit **outside his home county**. He was referred to the Learning Disability Team for discharge back into the community.

lan was inactive for most of the day and did not engage with the programme of activities on the unit. He was taking medication for his **extreme anxiety** and being frequently physically restrained. Following an assessment by the occupational therapist, lan was supported by the team's technical instructors to start **engaging with activities** that he was interested in.

**Designing support around lan's needs.** MENCAP staff had been commissioned to provide community support. The occupational therapist advised on a gradual community integration programme based on lan's goals. Having identified activities, that helped lan with his anxiety, the occupational therapist requested his medication be reviewed and reduced. The occupational therapist, also, assessed for **suitable housing**.

**Training to embed personalised care.** The occupational therapist and technical instructor staff remained involved throughout the transition process and provided regular sessional work both in Ian's home and community, advising MENCAP staff on resources and daily activities.

Ian has been discharged to a rented property **near to his mother's nursing home**. He is supported by MENCAP with 24-hour care provision which includes an 8-hour sleep-in and further 1:1 support.

### IMPACT

lan is taking **less medication** and has **improved mobility**. He has more control over his anxiety, resulting in **reduced use of restraint**.

lan attends church and prayer meetings, visits his mother and goes shopping. Ian cooks his own meals with **minimal support** and is supported with laundry, cleaning and gardening. He continues to **expand his experiences** and has recently been on a church holiday.

## Leading fulfilled lives

## Occupational therapy supporting people with learning disabilities

## To achieve the three recommendations contained within this report, services should deploy occupational therapy expertise so that...



## The RCOT Occupational Therapy Improving Lives, Saving Money campaign's overarching recommendations are:

To empower people to manage their health and wellbeing occupational therapists should be deployed across the health and care system to:

- **Intervene** early within primary care
- Embed personalised care through training and supervising others
- Develop wider partnerships to further innovation
- **Expand** therapy-led services

## Find out more: www.rcotimprovinglives.com

The Royal College of Occupational Therapists is a registered charity in England and Wales (No.275119) and in Scotland (No.SCO39573) and a registered company in England (No.1347374).

Royal College of Occupational Therapists



Occupational Therapy Improving Lives Saving Money #ValueofOT

## References

<sup>1</sup>United Nations, Department of Economic and Social Affairs (2006) *Convention on the rights of persons with disabilities*. Available at: *https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html* 

<sup>11</sup>Verdonschot MML, de Witte LP, Reichrath E, Buntinx WHE, Curfs LMG (2009) Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research*, 53, 303-318. doi:10.1111/j.1365-2788.2008.01144.x

<sup>iii</sup> Department of Health (2017) Local support for people with a learning disability. London: National Audit Office.

<sup>iv</sup> Emerson E, Hatton C (2011) *Estimating future need for social care among adults with learning disabilities in England: an update.* Durham: Improving Health and Lives Learning Disability Observatory.

<sup>v</sup>NHS Scotland (2017) *People with learning disabilities in Scotland: 2017 health needs assessment update report*. Edinburgh: Scotland.

<sup>vi</sup> Royal College of Nursing (2018) Learning disability care facing crisis. London: RCN. Available at: *https://www.rcn.org.uk/* news-and-events/news/learning-disability-care-facing-crisis

<sup>vii</sup> Nursing Times (2018) *Exclusive: half of learning disabilities nursing courses 'considering closure'*. London: Nursing Times. Available at: *https://www.nursingtimes.net/news/education/exclusive-half-of-learning-disability-nursing-courses-considering-closure/7024425.article* 

viii Great Britain.Parliament (2014) Care Act 2014. London: Stationary Office.

<sup>ix</sup>Welsh Government (2014) Social Services and Wellbeing (Wales) Act (2014). Cardiff: Welsh Government.

\*VODG (2017) STOMP Campaign. Available at: https://www.vodg.org.uk/campaigns/stompcampaign/

<sup>xi</sup> Galvin D, Wilding C, Whiteford G (2011) Utopian visions/dystopian realities: exploring practice and taking action to enable human rights and occupational justice in a hospital context. *Australian Occupational Therapy Journal*, 58(5), 378–385.

Perkes D, Whiteford G, Charlesworth G, Weekes G, Jones K, Brindle S, Hoare L, Todd E, Mililani R (2015) Occupationfocused practice in justice health and forensic mental health: using a practice-based enquiry approach. *World Federation of Occupational Therapists Bulletin*, 71, 101–107, doi:10.1080/14473828.2015.1103464

Smith HC (2005) 'Feel the fear and do it anyway': meeting the occupational needs of refugees and people seeking asylum. *British Journal of Occupational Therapy*, vol. 68(10), 474-476.

Uemura J-I, Hoshino A, Igarashi G, Nishio S (2018) Changes in activity: experience of new admissions to a long-term care facility. *Physical & Occupational Therapy in Geriatrics*, 36(2/3), 221-233.

Whalley Hammell K, Iwama M (2012) Well-being and occupational rights: an imperative for critical occupational therapy. *Scandinavian Journal of Occupational Therapy*, 19(5), 385-394.

Whiteford, G (2000) Occupational deprivation: global challenge in the new millennium. *British Journal of Occupational Therapy*, 63(5), 200-204.

Whiteford GE (2005) Understanding the occupational deprivation of refugees: a case study from Kosovo. *Canadian Journal of Occupational Therapy*, 72(2), 78-88.

x<sup>ii</sup> NHS Digital (2016) *Mental health and learning disabilities statistics*. London: NHS England.

xiii Welsh Government (2018) Patients in mental health hospitals and units. Cardiff: Welsh Government.

<sup>xiv</sup> Department of Health Northern Ireland (2018) *Mental health and learning disability inpatients 2017/18*. Belfast: Department of Health.

<sup>xv</sup> Scottish Government (2017) *Inpatient census*, 2017. Edinburgh: Scottish Government.

<sup>xvi</sup> Royal College of Occupational Therapists (2019) Making personalised care a reality: the role of occupational therapy. London: RCOT. Available at: http://cotimprovinglives.com/making-personalised-care-a-reality-the-role-of-occupational-therapy/