



# Five occupational rights: Principles to enable fulfilled lives when supporting people with learning disabilities

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# Introduction

'Occupations are any activity that we need, want or like to do to live and to look after our physical and mental health, and our emotional and spiritual wellbeing. We do occupations from the moment we are born on our own or with others. Occupations are essential to living. They give our lives meaning, purpose and structure. They help shape who we are, connect us with others and help create our identity and sense of belonging. Through occupation we enhance our health and quality of life.' (RCOT, 2023).

It is now over a decade on from the human rights violations exposed by the Winterbourne View. However, issues persist in the provision of care where individuals can continue to be institutionalised and occupationally deprived; isolated for long periods (Nicolle, 2021); with the potential of high levels of inactivity and boredom (Norfolk Safeguarding Adults Board, 2021). This is despite continued and rising levels of financial investment in services (Local Government Association, 2021).

*Good Lives: Building Change Together* (Learning Disability England (LDE) 2022, is a framework constructed by self-advocates and owned by the learning disability community; with acknowledgment that while people with learning disabilities highlight that 'they experience unfair treatment in some parts of their lives' (2022, LDE, p4) the focus of actions needs to be changing things for the better so that people can live their good life. This framework builds on previous work such as REACH standards (Warren & Giles, 2019), which provides a practical guide and manifesto to support people to live good ordinary lives as outlined by 'Stay Up Late' (2024).

This report originates from the challenge of continued rights violations impacting the lives of people with learning disabilities, and the continued ambition in self-advocacy for the enablement of people with learning disabilities to live full lives, underpinned by the UN General Assembly Convention on the Rights of Persons with Disabilities (2007). It outlines five occupational rights. These are key to supporting the promotion of occupation; daily activities; doing; contributing to, and being part of, all areas of life – to demonstrate that 'Good support is about life, not services'.

# About the development of the occupational rights

This report was developed by Dr Judith Reep and Dr Diana Ramsey in conjunction with the Royal College of Occupational Therapists (RCOT) National Executive Committee (NEC) for the Specialist Section for People with Learning Disabilities (SSPLD). It is a report that outlines the background and development of five occupational rights for people with learning disabilities. The occupational rights were co-designed with members of the Specialist Section and a self-advocacy group supported by the social enterprise Bemix, who shared their lived experience of engagement in occupation and its importance to them.

Thanks are extended to members of the self-advocacy group at Bemix and the RCOT Specialist Section members for their support in the development of the occupational rights. This document is designed to complement other publications such as the Good Lives Framework (LDE, 2022), Royal College of Speech and Language Therapists', Five Good Communication Standards (2013) and Standards of Practice for Physiotherapists Working with Adults with a Learning Disability (Bruce & Standley, 2020), which guided the thinking around the development of the rights. The occupational rights also sit in alignment with the revised National Learning Disability Professional Senate's guidance (2023).

## Summary of development and use of the occupational rights



# Recommendations

This paper recommends five occupational rights outlining occupational good practice. These rights aim to ensure that reasonable adjustments are made to support people with learning disabilities to engage in occupations that matter to them.

The occupational rights are intended to be a practical resource to support people with learning disabilities to live fulfilled lives; and families, carers, staff, providers, professionals, and commissioners to support them to do this. The occupational rights are suggested for use to identify what good occupational engagement looks like and to recognise when it is happening. It also highlights when and how to gain specialist support to enable and promote occupation in people's lives.

## Five occupational rights

- 1. The person has the right to choose what they do.**
- 2. The person has the right to have a balance of occupations.**
- 3. The person has the right for occupations to be made accessible.**
- 4. The person has the right to be free from barriers to occupations.**
- 5. The person has the right to occupations valued by themselves and their communities.**

In this report we've provided the theoretical background of the occupational rights in chapter 1. Within chapter 2 we've outlined the rights in detail.

# Chapter 1



**Background and application  
of the occupational rights**

# Theoretical background to the occupational rights



An inductive process was used to develop the occupational rights. This involved developing theory from experience in the real world and then comparing this with established theories rather than a theory led process (Grix 2004). The initial themes were developed from the experience of the authors working as occupational therapists with adults with learning disabilities and interacting with occupational therapists working in the field as part of the national specialist section. In addition to reviewing the various policies and reports and taking learning from their own research studies in this area (Reep, 2018, Ramsey et al, 2022).

Once the preliminary themes were developed, they were compared with findings from occupational science to consider if they matched with existing theories. Studies of occupational justice theory have highlighted the importance of occupation to a person and what can go wrong if there are no opportunities for this to occur. (Hocking, 2017)

## Five key concepts resonated with the themes that had emerged from practice.

### 1. Occupational alienation

Occupational alienation has been described as: 'deep feelings of incompatibility with the occupations associated with a place, situation, or others to the extent that basic needs and wants appear impossible to attain or maintain.' (Wilcock & Hocking, 2015 p 258). People with learning disabilities may experience occupational alienation if they are unable to choose what they want to do due to lack of support to make an informed choice, assumptions that they are not able to choose, institutional practices where choice is restricted, not enough support provided or attitudes that restrict options. A lack of choice may manifest as aggressive occupations associated with social unrest or self-destructive behaviours.

In order to avoid occupational alienation, the occupational right is proposed that the person has the right to choose what they do. This right is about supporting the person to make an



informed choice. It is not about allowing the person to do things that are detrimental to their health, for example eating harmful objects or not participating in any activities. If the person is not able to make a choice, there needs to be careful observation of the person engaging in activities to understand how they are reacting. Although, as for everyone, it is not possible to always do everything that a person wants to do, there needs to be balance overall that a person can make decisions so that they can meet their own needs and be able to negotiate and compromise with others. When supporting a person to plan their occupations it is important to have strategies including active listening; observing reactions and behaviours; supporting people to try out new or uncomfortable activities and give people opportunities to get used to them over time before supporting them to choose to engage in these again. Choosing occupations is an on-going dynamic process.

## 2. Occupational marginalisation

Occupational marginalisation is described by Hocking (2017) as when a person experiences discrimination or is offered education, work and other occupational opportunities and resources that are of least value in the community. People with learning disabilities are vulnerable to being marginalised by not being allowed to take part in a wide range of occupations due to their disability. They may also be impacted by additional protected characteristics that increase this likelihood such as gender, race, sexuality etc. It is often seen as acceptable that people are excluded from occupational opportunities due to a lack of skilled support.

In order to avoid occupational marginalisation, the occupational right that the person has the right for occupations to be made accessible is proposed. Instead of automatically discounting certain activities due to the person's disability, consideration should be given as to how the task can be adapted, changed, or made accessible. The person has a right to be supported to make these adjustments and to have access to skilled enabling support to engage in occupations.

## 3. Occupational imbalance

'Occupational imbalance is due to occupational patterns of being over or under occupied, due to excessive work demands, enforced idleness, or burdensome responsibilities to care for the environment, dependents or oneself.' (Hocking, 2017 p33). Some people with learning disabilities who live in settings where there is not enough support may not have the opportunity to have a balance of occupations. Family or paid carers may do things for the person rather than allowing them to do things for themselves, often out of perceived kindness, short term efficiency or to avoid potential risks. Others may not be able to succeed in certain roles such as parenting or employment due to a lack of support.

In order to avoid occupational imbalance, the occupational right is proposed that the person has the right to have a balance of occupations. People with learning disabilities may need support to recognise when their balance of occupations may be detrimental and to consider alternatives.



## 4. Occupational deprivation

'Occupational deprivation points to externally imposed barriers to valued, meaningful occupations necessary for well-being.' (Hocking, 2017 p33). At its most extreme, Baroness Hollins (2023) highlights, in her final report, the lack of therapeutic benefit of the continued use of solitary confinement for people with learning disabilities and autistic people. Noting that confinement, hospital routines and environments add to further traumatised people, who are exposed to sensory and social deprivation for lengthy periods of time. While certain inpatient ward environments demonstrate higher degrees of occupational deprivation, externally imposed barriers to valued activity engagement can be a feature of many people's lives for those living in supported care environments.

In order to avoid occupational deprivation, the occupational right is proposed that the person has the right to be free from barriers to occupations. Positive risk taking is required to ensure that access to occupations is always supported.

## 5. Occupational apartheid

Occupational apartheid is when there is an overall segregation of groups of people in society; in which access to occupations such as quality education, well-paid work or leisure are denied, due to prejudice about their abilities or not perceiving them as being entitled to the same culturally valued occupations that others benefit from in society. (Wilcock & Hocking, 2015). This continues to be demonstrated by the stubbornly low rate of 4.8% of people with learning disabilities being in paid employment in England (2022, NHS Digital).

To avoid occupational apartheid, the occupational right is proposed that the person has the right to occupations that are valued by themselves and their community. People with learning disabilities need to have opportunities to be active participants in their communities. This is not about excluding people from spending time with other people with learning disabilities, if that is what they would choose to do, but enabling a wider variation of opportunities. Occupational apartheid can occur if a person is not treated with respect and is considered to be dependant and unable to do activities.



# Application of the occupational rights

## Summary of how the occupational rights should be applied

### Occupational therapists' role

<b>Specialist</b>	Occupational therapists working in learning disability services provide intervention and assessment with people whose primary reason for referral relates to the effect of their learning disability upon their occupational performance.	Occupational therapists working in learning disability services provide expertise in enabling occupational rights.
<b>Targeted</b>	Occupational therapists working in learning disability services should work collaboratively with others to enable them to meet the occupational performance needs of people with learning disabilities.	Occupational rights need to be met by all those who directly support people with learning disabilities.
<b>Universal</b>	All occupational therapists need to ensure they make the reasonable adjustments in order that people with learning disabilities can access their service.	Everyone who interfaces with people with learning disabilities need to support their occupational rights.

### Learning disability occupational therapists' specialist core role:

- to promote the occupational rights
- to identify when the occupational rights are not being met
- to promote and facilitate universal training as to how to support occupational rights
- to address the occupational needs when, due to complexity, they require specialist occupational therapy input.

Enabling people with learning disabilities to meet their occupational rights should be the universal role of everyone in society. Opportunities should be made available and there should be an expectation that fulfilling occupational rights is essential. Those involved in supporting people with learning disabilities need to understand their role and develop skills in enabling occupational rights. Occupational therapists working in specialist learning disability services have expertise in enabling people with learning disabilities in meeting their occupational rights, which can be provided by direct assessment and intervention with an individual or by providing advice and training to the person's wider network (see below).

## Occupational therapy in learning disabilities specialist principles

Learning disability specialist occupational therapy principles

### Principle 1

Occupational therapists working in learning disability services provide a service for people whose primary reason for referral relates to the interaction of their learning disability with the five occupational rights.

### Principle 2

Occupational therapists should offer assessment and intervention to people with learning disabilities that focus on meeting the occupational rights.

### Principle 3

Occupational therapists should work collaboratively with carers and all relevant agencies to meet the occupational rights of people with learning disabilities.

### Principle 4

Occupational therapists should promote the expectation that people with learning disabilities should have their occupational rights met.

### Summary

The occupational rights have been developed from practice and are set out in detail in Chapter 2. We've created an easy read version of the occupational rights which is available on our website.

# Chapter 2



Five occupational rights



# Five occupational rights

1. The person has the right to choose what they do.
2. The person has the right to have a balance of occupations.
3. The person has the right for occupations to be made accessible.
4. The person has the right to be free from barriers to occupations.
5. The person has the right to occupations valued by themselves and their communities.



## 1. The person has the right to choose what they do:

- 1.1 The person is given opportunities to spend time doing what they have chosen to do.
- 1.2 A record is kept of what the person values doing. This can be created with their network.
- 1.3 The person is supported to make choices about what they want to do, free from assumptions and undue influence by others.
- 1.4 If the person's choice of occupations is detrimental to their health, they are supported to understand the consequence of the choice and alternatives are suggested.
- 1.5 If the person lacks capacity, they are still supported to take part in a balance of occupations following a best interest process.
- 1.6 The person is offered support and expert assessment as required if they struggle to choose activities.

### What people with learning disabilities said:

“

**I like doing things for my friends, hanging around with my friends.”**

“

**Nobody should say that. Nobody should say not allowed to do this.”**

## 2. The person has the right to have a balance of occupations:

- 2.1 The person is supported to live a fulfilled life, with a balance of occupations including work, leisure, education and self-care.
- 2.2 The person carries out occupations that are person centred and meet their physical and mental health needs.
- 2.3 The person is supported to have opportunities to explore and develop a range of interests.
- 2.4 The person is offered support and professional assessment, including positive risk assessment, if they wish to do occupations that are difficult for them.

### What people with learning disabilities said:

“

**I go to bingo.”**

“

**I like going  
on holiday.”**

“

**I like to go  
out late in  
the evening.”**



### 3. The person has the right for occupations to be made accessible:

- 3.1 The person is supported to engage in activities and to develop their skills.
- 3.2 The person's communication, sensory, physical and mental health needs are understood and taken into account by people supporting them in occupations.
- 3.3 The person is supported in a consistent way to engage in occupations and learn skills.
- 3.4 The tasks that the person does are adapted according to their individual needs.
- 3.5 The person and their carers can seek training, support and/or expert assessment around adapting occupations to meet individual needs.

### What people with learning disabilities said:

“

**I will do everything myself, but sometimes, if I feel stressed or tired, I will say if I need help, but I will try and persevere.”**



## 4. The person has the right to be free from barriers to occupations:

- 4.1 The person's physical, sensory and social environment is set up to enable them to participate in occupations.
- 4.2 The person has support available that prioritises enabling occupation.
- 4.3 Positive risk taking is promoted for the person to participate in valued occupations.
- 4.4 The people supporting the person are competent in active engagement and skills teaching and understand their individual needs, seeking expert advice as required.
- 4.5 Restrictive environments and poor support which prevent people engaging in occupation are robustly challenged.

### What people with learning disabilities said:

“

**Sometimes when I go out, I want to stay out late, but I basically, one of the rules where I am living, I can't stay out late unless it's a planned event.”**

“

**I have the right to take risks.”**

“

**I live in the countryside. In October, every single bus is going to stop going there. The nearest train station to them is three miles and it's through completely dark country roads.”**

## 5. The person has the right to occupations valued by themselves and their communities:

- 5.1 The person is supported to be included in a wide range of occupations and roles in and outside their home.
- 5.2 The person engages in roles that are valued by themselves and the people around them.
- 5.3 The person is supported to follow goals and challenge expectations throughout their lifespan.
- 5.4 The person is offered support and expert assessment when required, to have occupations that enable community inclusion.

### What people with learning disabilities said:

“

**My main goal is to get a paid job so that I don't have to rely on my mum and benefits.”**

“

**He said he wanted to learn to dive when he saw my photographs inside wrecks under the sea. So, we went to the group, and they were great. They said he could do it and it took a long time. But now we do dive together, even though I have to hold him all the time as he goes around in circles.”**

“

**Always, always have to work in the back – I am not asked to work on the shop floor.”**

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