



**Supporting People
with Intellectual
Disabilities to
Have a Good Life
as They Grow Older**
A self-study guide



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Christine Towers
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Introduction

Why training on good support for people with learning disabilities who are growing older is important

People with learning disabilities are living longer, and it is only within recent decades that many people with learning disabilities have begun to live into their 60s and beyond. Furthermore, until relatively recently, people with learning disabilities have aged while living with their families or in residential homes. It is now increasingly common for people with learning disabilities to be living more independent lives and are therefore ageing in supported living, either in shared houses or flats, or in their own flat, with a wide variety in levels of support.

The recent nature of this longer life expectancy and people aging in more independent settings means that there is limited knowledge about how best to adapt support for people as they age to ensure they can enjoy opportunities and feel safe and well in later life. Expectations have also increased for people's quality of life and, whether people are living in supported living, residential or nursing care, there is an understanding that people have the right to person-centred support that provides opportunities and promotes well-being.

This book and the training pack that can be used alongside it, aim to contribute to the development of our knowledge about supporting people as they age; to raise the expectations of older people with learning disabilities and their families and friends; and to raise the aspirations of individuals and services providing support.

Another reason why this training is important is discrimination and isolation. While these are often experienced by people in the general population as they age, they are particularly true for people who haven't been in a position to build up assets (such as a home of their own or a work-based pension) during their adult life. People with learning disabilities face discrimination and exclusion throughout their lives and potentially face the double jeopardy of being older with limited assets and having a learning disability.

There has been huge steps forward in recent years to end age discrimination, and generally there is an acceptance that society must give people the opportunity to age well. There is a plethora of information on ageing well and 'active ageing' covering aspects of life such as physical health, positive mental health, keeping active, being safe at home and maintaining independence for as long as possible. There is much to be learned from this approach to provide

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good support to people with learning disabilities as they age, and this book is shaped by the idea that people with learning disabilities have the same right to 'active ageing' or ageing well as anyone else.

Another potential reason for exclusion is the separate nature of support for older people in the general population and support for people with learning disabilities who are older. Older people with learning disabilities sometimes fall between the services offered for older people and those for people with learning disabilities, whereas in older age they may benefit from joined up thinking from across both support pathways. It is hoped the approach to providing good support in these training resources will build links across services for people with learning disabilities and older people more generally.

The purpose of this training resource

The purpose of this training is to contribute to improving the quality of life of people with learning disabilities as they grow older, through improving the quality of support they receive. This study guide offers good practice ideas in relation to accessing opportunities to have an active and enjoyable life while also being supported to be safe and well. The information should be useful for anyone providing support to people with learning disabilities as they get older, and also to those managing support services, commissioning support, and shaping and reviewing care and support plans. It will be a useful handbook for personal assistants, support workers and senior workers in supported living, residential and respite care and day opportunity services.

This study guide may also be helpful for family carers to think about what support they would like their relative to receive whether they live in the family home or elsewhere to know what good support should look like and to check the quality of the support their relative is receiving, and also to have conversations with their relative to decide the best use of support hours or to discuss at an annual review of a care and support plan or an assessment of need.

These training resources could also be used by community and voluntary organisations looking to be more inclusive of older people with learning disabilities, and by support services for older people who want to improve their offer to older people with learning disabilities.

It is also hoped that using these training resources will increase the job satisfaction experienced by support workers and others in services and organisations. There is significant scope to engage with people to find out how they are experiencing older age, looking together for solutions to difficulties and being led as much as possible by the person to achieve what they would like from older age. This should create an ongoing learning cycle for support workers thereby increasing their knowledge and skills as well as enjoyment at work. This approach doesn't necessarily require more resources, only for them

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to be used differently, and good outcomes can be achieved even when people are only receiving a low level of support.

The underlying values of the training resources

People have the right to a good life made up of being safe and well alongside having opportunities to do enjoyable and meaningful activities. Support should be based on a basic right to have choice and control, maintain as much independence as wanted, and be able to participate in groups and activities that are of interest to the person and to learn new things.

This training is underpinned by three key approaches:

- Person-centred thinking and planning to help understand what really matters to a person, building on their strengths, ensuring they are listened to and are at the centre of decision-making about what happens in their life.
- Good communication with the person being supported, and others who know them well.
- Encouraging participation, choice-making and independence.

Most of the exercises promote a practical approach to improving the quality of support and encourage participants to note how their learning can improve their day-to-day practice. All of the ideas in the exercises can be adapted for people with more severe or profound levels of disability, but they are likely to require supporters to use specific approaches in communication that they know work for the person, as well as talking to others who know them well.

How they were developed

The materials are based on current knowledge about what supports people with learning disabilities to have a good life as they age. Some of this evidence comes from research papers, while other evidence comes from talking with people with learning disabilities about their experience of ageing and what was important to them in the support they received. Further corroboration came from the author's experience of delivering a quality assurance programme across a wide range of support services as well as developing and managing services over many years.

As these training resources were being developed, the author talked with people with learning disabilities about what is important to them as they get older. At two centres that provided day time opportunities for older people with learning disabilities, she explored ideas such as what helped them to remain active, how they liked to be supported to look after their health and ways in which they would like to remember family and friends who had died. In addition, Ian Davies, who has been an active self-advocate for around 30 years, shared his experiences of growing older and his thoughts on good support. He also contributed to the filming for the video clips used in the training materials.

What was apparent from talking to Ian and the other people who contributed, is that people with learning disabilities have very little opportunity to speak on their own or as a group about growing older and the support they would like to have to continue to enjoy life and to feel safe and well. Before working on these training materials, Ian hadn't spoken in any depth about growing older and, after doing so, he was clear about the importance of people being given the opportunities to talk and be listened to. The training therefore has a focus on encouraging conversations about growing older. Some people will be able to engage in verbal conversations, perhaps with the help of images, photographs and objects. For others it will mean spending time with a person to get a sense of what's important to them, what works and doesn't work in relation to organising support, and talking with people who know them well.

The structure of the training materials

There are two parts to the training materials: this self-study guide and a separate training manual. The manual is a guide for leading group-based training. Both parts of the training materials cover the same topics and have similar material and exercises.

Self-study guide

This self-study guide is designed for people to use on their own, either for their independent learning or as part of training and development within a service or organisation. Whichever route you are following, it is important to have someone with whom you can discuss your reflections, ideas and learning. If you are studying as part of your work you should aim to discuss your learning in supervision time, team meetings if appropriate, and hopefully there will also be time for group feedback and discussions with fellow learners. If you are studying independently you could find a mentor, colleague or 'study buddy' with whom to discuss your learning.

The training covers six topics:

- Understanding growing older.
- Emotional well-being.
- Health.
- Being active and involved.
- Home life.
- Bereavement and dying.

The first chapter is an introduction to the key ideas around growing older and what this may mean in the lives of people with learning disabilities. The other five chapters cover key aspects of people's lives as they grow older.

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Each chapter stands on its own although it would be recommended to study them in the order they are presented. Completing the six chapters will take around seven hours of learning although it would be preferable to break this up into either three or six sessions. Allocating time to think about the reflections and tasks will maximise learning opportunities and the development of ideas that can be transferred to your place of work.

Each chapter starts with the aim and learning outcomes. This is followed by an introduction and three exercises to explore different aspects of the topic. Each exercise has a short task which provides an opportunity to use your learning to build a portfolio of ideas for you to use in your support setting. Some of the chapters have video clips to play. Some of these are of Ian Davies talking about his experience of growing older and others are of the author sharing her learning from talking with people with learning disabilities and supporting people who are growing older.

At the end of the guide there are links to resources and recommended further reading for people who would like to continue to learn more (page 73). Some of these are referred to at relevant points in the topics.

The training pack

The training pack is designed for group-based learning and includes:

- PowerPoint presentations for the training.
- Suggestions for how to deliver the training, including exercises, learning cycle questions to look at a topic in more depth, and tips for trainers to help them deliver the training.
- There are links to the videos of the author and Ian Davies to reinforce the learning in topics.
- Learning resources with additional information and templates to write down ideas from exercises.
- A participant's learning portfolio.
- A copy of the self-study guide.

The film clips

Throughout this book you will be directed to watch certain film clips to enhance the specific learning point being discussed, and there also suggestions for other clips that can be watched optionally. All the clips are available at www.pavpub.com/supporting-older-people-resources.

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In these film clips you will meet Christine Towers, the author of the training materials, and Ian Davies, a self advocate.

Now might be a good time to watch **Film Clip 1.1: Introducing Christine and Ian.**

Chapter 1: Understanding growing older

Aim and learning outcomes

The aim of this chapter is to gain an understanding of the different aspects of growing older and how people with learning disabilities may experience them.

It will help you to:

- Gain a broad understanding of what is meant by ‘growing older’.
- Understand how people with learning disabilities usually approach older age with disadvantages when compared with the rest of the population.
- Gain good practice ideas when supporting people with learning disabilities as they get older.

Introduction: understanding growing older

This book and the training that accompanies it focuses on the changes people experience as they get older and provides ideas for helping people to have a good quality of life, helping them have a positive experience of ageing and enabling them to remain as active and involved as possible. The book specifically addresses the period of life before people become more frail and may need a much higher level of care to prevent them from being at risk. However, much of the content could also be relevant at this time of life.

This opening chapter looks at what growing older means in the lives of people with learning disabilities, and it explores key approaches for providing people with support that is enjoyable and meaningful.

There are three exercises on the topic of understanding growing older for you to read and then undertake short tasks:

1. What does growing older mean to you?
2. The experience of ageing for people with learning disabilities.
3. Key approaches to providing good support to age well.

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1. What does growing older mean to you?

Growing older is something we all experience and our thoughts about this will depend on many different factors such as our own age, the age of people we are connected to as well as our background and culture.

Reflection

What does 'growing older' mean to you? Think about your family and friends: whom amongst them do you think of as getting older, and why?

There are two ways of looking at ageing. It can be seen as:

1. Adding on years, which is the chronological process of ageing.
2. A loss of function or ability over time, which is the biological process of ageing.

The loss of function and ability is only loosely related to chronological age. Therefore, reaching a certain age does not correspond with needing help with certain tasks or finding specific activities more difficult.

There is no specific age at which people are described as 'older', but the ages of 60 and 65 are often used to define 'seniors', and this term is loosely related to previous retirement ages. However, in 2012 the default age of retirement of 65 was abolished and the age of entitlement to state pension has been increasing in stages in the light of longer life expectancy.

A key point is that people with learning disabilities usually experience biological processes of ageing at a younger chronological age than the rest of the population.

Watch **Film Clip 1.2: People age differently**, which explains that getting older cannot be defined as reaching a specific age but is a process with numerous gradual or sudden changes over time.

It is important to remember that change may not just be in one direction, for example people may regain skills after a period of illness or after living with pain. It is also important to recognise that there will be many variations between people who are of a similar age. Therefore, what is important to think about, for example, for one 60-year-old person you support may not be relevant to another person of a similar age.

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The recent nature of these changes means that we have limited knowledge about how best to adapt support for people as they age to ensure they can enjoy opportunities and feel safe and well in later life. This book, and the training pack that can be used alongside it, aim to contribute to the development of this knowledge; to raise the expectations of older people with learning disabilities and their families and friends; and to raise the aspirations of individuals and services providing support.

This study guide offers a wide range of good practice ideas for accessing opportunities so people can enjoy active and fulfilling lives while also being supported to be safe and well. It covers six topics: understanding growing older; emotional well-being; health; being active and involved; home life and bereavement and dying. The information will be useful for anyone providing support to people with learning disabilities as they get older, and also to those managing support services, commissioning support, and shaping and reviewing care and support plans. It will be a useful for personal assistants, support workers and senior workers in supported living, residential and respite care and day opportunity services.

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