

# in **Focus** **ldt**

## Living well with a learning disability

January 2024  
Volume 1  
Sample issue

In collaboration with

**activity  
alliance**  
disability  
inclusion  
sport

**STAY UP  
LATE**

# Contents

January 2024 Volume: 1 Sample issue

## 03 Letter from the editor

Lauren Nicolle, Editor, *In Focus*

## 04 Fostering independence in adults with learning disabilities

Lauren Nicolle, Editor, *In Focus*



## 08 How can we support people with learning disabilities to be active?

Wilf Reeve, Media and Campaigns Advisor, *Activity Alliance*

## 12 Nutrition and diet: supporting people with learning disabilities to make healthy choices

Lauren Nicolle, Editor, *In Focus*

## 16 What matters to you? The importance of hobbies, interests and having fun

Florence Little, Campaign Coordinator, *Stay Up Late*

## 20 Sex, love and learning disability

Alison Bloomer, Editor, *Learning Disability Today*

## 24 Empowering people with learning disabilities to gain employment

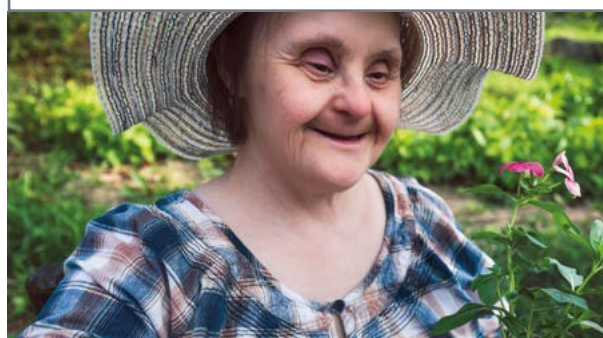
Employment Team, *Mencap*

## 26 Is living a good life still a pipe dream for people with a learning disability?

Lisa Hopkins, CEO, *SeeAbility*

## 28 Healthy ageing and Down's syndrome

Alison Bloomer, Editor, *Learning Disability Today*



# Letter from the editor



**Lauren Nicolle,**  
Editor, *In Focus*

There are 1.5 million people with a learning disability in the UK, many of whom need support to be able to live independent lives. Behind them are family members, support workers and carers who work hard to provide the best care possible.

Access to information and resources is vital to ensure family members and carers are equipped with the tools they need to provide good care; but this information can be hard to find, scattered across multiple sources, making it difficult to stay up to date with the latest advice and guidance.

Our new magazine, *In Focus*, is dedicated to people with learning disabilities, their family members, carers and other professionals involved in their care. It is a quarterly, themed publication, which groups together all the latest evidence in one place. This magazine is designed to shine a light on good practice and provide practical tips and resources to improve the lives of people with learning disabilities.

We believe good practice should be shared and celebrated as often as possible. It can provide a valuable lifeline for carers and family members, yet it often goes unnoticed. Instead, media headlines are often dominated with care failings and avoidable deaths. We believe those involved in the care of learning disabilities should be provided with the resources to change this narrative and ensure everyone with a learning disability is given the care and life they deserve.

Each issue of *In Focus* will act as a resource pack for those involved in the care of people with learning disabilities. This year, we will publish issues on transitioning to adult services, housing, employment and healthcare, with input from those with lived experience, charities and experts in the field.

This introductory issue explores how carers can support people with learning disabilities to live a happy, healthy life. Inside, you will find articles on relationships, socialising and having fun, as well as exercise, nutrition and employment. We have also included external links to a wide variety of helpful resources which you can explore at your leisure.

I hope this magazine proves to be an invaluable resource for those that need it. If you have any suggestions on what you would like to see covered in future editions, please drop me an email at [lauren.nicolle@pavpub.com](mailto:lauren.nicolle@pavpub.com). I look forward to hearing from you.

---

The only way to look after the needs of people with learning disabilities is to look after the needs of the people who care for them”



**Robert Jones**, author of *'The Art of Caring for People with Intellectual Disabilities'*.

# Fostering independence in adults with learning disabilities

Adults with learning disabilities can lose their independence when they move out of the family home. This article highlights why independence is vital for wellbeing and overall quality of life, as well as providing practical tips for carers on how they can foster independence and help people with learning disabilities to achieve their goals and ambitions.

Independence is a key factor in mental health and wellbeing. It allows for personal growth and development, self sufficiency and can lead to an overall better quality of life. However, people who rely on others for support to meet their basic needs can easily lose their sense of independence and feel as though they have lost control over their lives. This can exacerbate feelings of anxiety, depression and loneliness.

“ . . . independence is one of the key principles of the Care Act 2014

Losing independence is therefore a primary concern for many people with learning disabilities who move into residential care, but it can also be a concern for those receiving high levels of support in the community. This is because the person can become reliant on their carer or support worker to perform tasks for them, such as making meals and helping them get dressed. They may also have less control over their routine and how they spend their time and money.

**Lauren Nicolle**, Editor, *In Focus*

For some people, particularly those in inpatient care, this loss of independence can be extreme, and people can lose the ability to make simple decisions such as what they will eat for breakfast and when they will spend time outdoors. This can be extremely damaging to a person's mental health and wellbeing.

This is why independence is one of the key principles of the Care Act 2014. The Act recommends that all carers promote a person-centred approach to the support they provide, allowing people to have control and autonomy, and make key decisions in their day to day lives (Figure 1).

People with learning disabilities should be asked about their goals and the outcomes they want to achieve, and they should be encouraged to participate in activities that they enjoy. This can help the person to create new relationships with people outside of their immediate circle and help them to learn and retain new skills, improving overall quality of life. It can also improve self-esteem, reduce demand, dependency and loneliness, and provide a sense of long-term stability.

However, with hundreds of thousands of vacancies across the social care sector, providing person-centred care for every individual can easily fall down the priority list, particularly in residential care. So how can time pressed carers help people with learning disabilities to take charge of their own lives?

## **The importance of providing person-centred care**

People with learning disabilities can maintain their independence when they receive excellent care, whether that be in the community or in a care home. This will require carers to take a

**Figure 1. Principles of the Care Act 2014**

- The Care Act 2014 was designed to put people and their carers in control of their care and support. It helps to improve people’s independence and wellbeing and strengthen the rights of people with a need for care and their family carers.
- Under the Act, local authorities are required to involve adults in their assessment, care and support planning and review.
- A person can receive part or all of their personal budget as a direct payment to facilitate independence. Direct payments enable a person to exercise the maximum possible choice over how they are supported, who they are supported by and where they are supported.
- Local authorities are bound to the principles of the Care Act 2014 and they have a legal duty to prevent, reduce and delay people’s needs from worsening.

**Source: Care Act 2014 Principles, CPD Online College**



person-centred approach, allowing the person they care for to participate in decisions about how they spend their time. Even when someone has reduced capacity to make decisions, promoting independence is still important by giving the person as much control as is possible and sensible.

**Pursuing hobbies and interests**

Every person with a learning disability is a unique individual with their own needs, preferences and life experiences. As such, they should be asked about their hobbies and interests and what matters to them. Allowing people to choose how they spend their time improves quality of life and overall wellbeing.

Care providers and givers should consider who the important people are in the person’s life, what the person’s strengths and weaknesses are and what is important to the person, i.e. their goals and ambitions. Carers must then consider what kind of support will be needed to help the person maintain these relationships, achieve their goals and where people may need extra help and guidance.

**Developing skills**

People with learning disabilities should be empowered to learn and develop new skills for themselves. The learning disability charity

People with learning disabilities can maintain their independence when they receive excellent care



Macintyre recommends that carers should resist the urge to step in and do everything for the person. Instead, carers should work side-by-side with the person they support, maximising what the person can do and supporting them with anything that they are struggling with.

This does not mean that people with learning disabilities are completely left to their own devices, but rather that they are supported when necessary, rather than all of the time. It is important that all aspects of daily life are considered and independence is balanced with support and care. The National Institute for Health and Care Excellence (NICE) refers

to this as ‘positive risk-taking’, i.e. thinking about the benefits of taking risks, as well as the drawbacks of avoiding them.

### Effective communication

NICE recommends that all staff delivering care services practice effective communication skills. Good communication is key to fostering independence, and open conversations can help the person feel respected and valued, which in turn leads to a happy and fulfilled life.

Communication styles may need to be adjusted for the individual. Straight forward language should always be used, while some may need added extras such as pictures, photos and symbols. Makaton and other inclusive communication styles may also be used when necessary.

“ People with learning disabilities should be empowered to learn and develop new skills for themselves

If you notice someone losing their independence, Macintyre recommends voicing this within team meetings and putting an action plan in place for the person. This fosters a culture of independence across care teams and ensures no one slips through the cracks.

### What does good practice look like?

Disability charities strongly support the idea that every person with a disability has the right to choose where and who they live with, and how they spend their time. People with learning disabilities should have the same freedom, choice, dignity and control over their lives as everyone else. This does not mean living a life without support, but that support should be provided in a way which allows equal participation in society and choice over how to live your life.

Community living often gives people with learning disabilities the best chance at living an independent, good quality life. Living nearby to family and friends and being actively part of the community is often important and out of area placements can leave people with learning disabilities feeling disjointed from

their communities, exacerbating feelings of loneliness and isolation.

When people with learning disabilities need high levels of support, residential care may be necessary. These care homes must be adapted to meet the requirements of the people supported there, and specialist equipment, such as personalised technology, can help people living in care homes to live their lives as independently as possible.

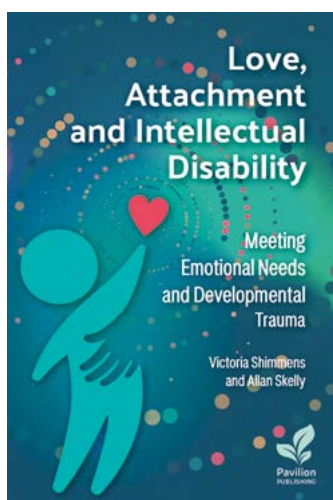
The learning disability charity Hft, for example, encourages every person they support to take part in as many everyday activities as they can. Whether they are supported in residential care or in the community, Hft allows the people they support to choose their staff, decorate their room however they like, enjoy leisure activities and work to achieve specific goals (such as getting a job).

Hft says involvement can be as straightforward as developing skills that other people take for granted, such as supporting people to eat and drink on their own. “It’s all about giving people as much opportunity to live with independence and choice as possible,” the charity says.

### Resources

- Care and support statutory guidance: <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>
- Providing person-centred care: <https://www.scie.org.uk/prevention/choice/person-centred-care>
- Leading an independent life: <https://www.macintyrecharity.org/news-blogs/leading-an-independent-life-with-a-learning-disability-and-dementia/>
- Managing money: <https://www.scope.org.uk/advice-and-support/managing-money-for-someone-else/>
- Effective communication: <https://www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability>
- Housing guidance: <https://www.mencap.org.uk/advice-and-support/housing>
- Fostering independence in residential care: <https://www.hft.org.uk/our-services/residential-care>

# ldt<sup>in</sup> FOCUS



## Love, Attachment and Intellectual Disability: Meeting Emotional Needs and Developmental Trauma

Victoria Shimmens, Allan Skelly

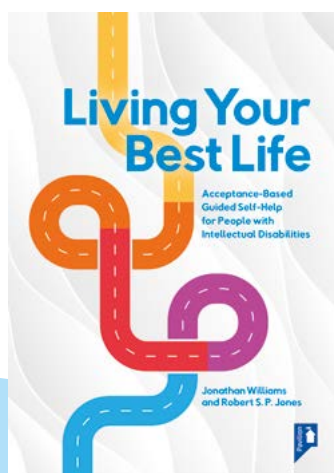
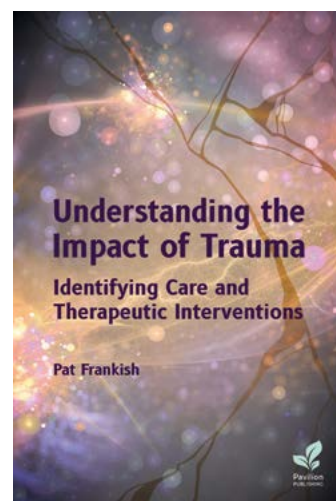
The book *Love, Attachment and Intellectual Disability* highlights the importance of early attachment and the trauma that can occur when this basic emotional need is not met.



## Understanding the Impact of Trauma: Identifying Care and Therapeutic Interventions

Dr Pat Frankish

This title follows the success of the FAIT, an assessment tool for determining the level of emotional development in individuals with intellectual disabilities, and explores the usefulness of applying this model more broadly to anyone who has experienced trauma.



## Living Your Best Life: Acceptance-Based Guided Self-Help for People with Intellectual Disabilities

Jonathan Williams, Robert S. P. Jones

*Living Your Best Life* is an activity-based workbook that guides people with intellectual disabilities to identify what really matters to them and to live their best lives.



For more Learning Disability titles visit  
[www.pavpub.com/learning-disability](http://www.pavpub.com/learning-disability)

# How can we support people with learning disabilities to be active?

**W**hile the benefits of exercise and physical activity are indisputable, disabled people are still twice as likely to be inactive compared to non-disabled people. Here, Wilf Reeve, Media and Campaigns Advisor at Activity Alliance, explains what needs to be done to tackle this ‘fairness gap’.

Providing physical activity opportunities for people with learning disabilities is a key component of building a healthier and more inclusive society. There are numerous mental and physical health benefits that can be gained through sport and activity. However, we live in a world where disabled people face significant barriers when trying to be active. This means disabled people are almost twice as likely to be physically inactive (43%) compared with those without a disability (23%).<sup>1</sup>

“The picture for people with learning disabilities is similar to the worrying trends seen in disabled people overall

These barriers are highlighted every year in black and white by Activity Alliance’s Annual Disability and Activity Survey. The most recent survey, published in June 2023, found that the rising cost of living and its wider impact is having a negative effect on disabled people’s activity levels and their wellbeing.<sup>1</sup> It

**Wilf Reeve**, Media and Campaigns Advisor, *Activity Alliance*

also highlighted worrying signs of increasing loneliness among disabled people over the last four years compared to decreasing levels of loneliness for non-disabled people.

## Addressing the ‘fairness gap’

Activity Alliance believes that it is simply not right that disabled people are the least active in our society, and as a national charity and leading voice for disabled people, we have set out to address this ‘fairness gap’ and create a society where everyone can be active however and wherever they want to be.

The data derived from our annual disability and activity surveys is incredibly useful for organisations working to reduce activity barriers for those with disabilities, as it reveals where the gaps are in activity provision and what needs to be done to create more equal opportunities – a crucial insight when trying to enact meaningful change.

The picture for people with learning disabilities is similar to the worrying trends seen in disabled people overall. Last year, 75% of people with learning disabilities said they wanted to be more active, but a lack of opportunities prevented them from doing so.<sup>1</sup> In fact, 46% of people with learning disabilities said they were not given the opportunity to be as active as they wanted to be, compared to 39% of disabled people and 22% of non-disabled people.<sup>1</sup>

Furthermore, compared to disabled people overall, people with a learning disability were more likely to be motivated to take part in sports or physical activity to improve or maintain their mental health and meet new friends (18% vs 10%).<sup>1</sup> These statistics serve as a powerful reminder of the urgent need to

address the barriers inhibiting individuals with learning disabilities from leading active and healthy lifestyles.

### The 'Get Out Get Active' programme

Like other disabled people, people with learning disabilities said that their disability often stops them from being as active as they would like (65% vs 80% of all disabled people).<sup>1</sup> The reasons for this were confidence issues (49%), previous bad experiences (33%) and negative attitudes from others (27%).

People with learning disabilities also said they commonly experienced barriers to physical exercise such as a lack of finances (32%) and suitable transport (18%), while eight in 10 said Covid-19 and the resulting restrictions affected their ability to do exercise.<sup>1</sup>

With insight and expertise from disabled people, it is possible to challenge existing practice and develop new approaches to delivering sport and activity for disabled people.

One such example is Get Out Get Active (GOGA), a UK-wide programme that supports disabled and non-disabled people to enjoy being active together. The programme reaches out to people that stand to benefit the most from being more active, improving both physical health and mental wellbeing. This is done through locally driven outreach. Each area has a unique community focus and approach to engaging those that are least active, such as disabled people and those living in isolated communities.

It supports disabled and non-disabled people to be active together through genuinely inclusive environments, and it has had extraordinary results since its inception in 2016. More than 130,000 people have been reached in seven years, with eight in 10 people reporting improvements in their mental wellbeing after taking part in GOGA activities.<sup>2</sup>

### The benefits of physical activity

Recognising the importance of sports for people with learning disabilities goes beyond the physical benefits. While engaging in regular physical activity is crucial for maintaining good health, sport also serves as a powerful catalyst for social inclusion, personal development, and improved mental wellbeing.

It provides a platform for social interaction, fostering a sense of belonging and community.



... almost a third of disabled children and young people are classed as inactive



Participation in team sports or group activities helps break down social barriers, promoting connections and friendships that extend beyond the field or court.

Physical activity also has a profound impact on mental health. Sports and activity offer an outlet for stress and emotions, and allows for the development of coping mechanisms. For individuals with learning disabilities, this can be particularly transformative, especially when you consider that just 2% of people with learning disabilities reported a very high life satisfaction in our 2023 Annual Disability and Activity Survey. Similarly, only 3% say they feel happy all or most of the time and just 6% feel their life is worthwhile.<sup>3</sup>

### The importance of getting active from an early age

Positive experiences with physical exercise can have an enormous impact from an early age, setting people up to enjoy an active life, but currently, only a small number of disabled children are physically active.

Findings from Activity Alliance's *My Active Future* report in 2020 highlights the activity gap between

disabled and non-disabled children, showing that one third (30%) of disabled children are 'less active' or inactive (exercising for 30 minutes or less per day) compared to 21% of non-disabled children.<sup>4</sup>

Furthermore, only a quarter (25%) of disabled children say they regularly take part in sport and activity at school compared to 41% of non-disabled children. This only gets worse with age, with disabled children's activity levels decreasing significantly as they get older.

## Inclusion 2024

The fact that almost a third of disabled children and young people are classed as inactive shows the amount of work that still needs to be done. That is why programmes such as Inclusion 2024 are so vital.

“ . . . only a quarter (25%) of disabled children say they regularly take part in sport and activity at school compared to 41% of non-disabled children

This programme aims to increase and improve opportunities for young people with special educational needs and disabilities (SEND) to engage and participate in physical education and school sport. The project is funded by the Department of Education and led by the Youth Sport Trust on behalf of a consortium of organisations including Activity Alliance, the British Paralympic Association, National Association for Special Educational Needs and Swim England.

The Inclusion 2024 education hub (<https://education.activityalliance.org.uk/>) enables teachers and school staff to privately self-assess their inclusion of disabled students in PE and school sport. It is built based on the growing concern that many disabled children continue to miss out or have negative experiences in PE and school sport, enabling schools to assess their current approach to inclusion and access a personalised report with advice and resources to improve their practice.

Activity Alliance has developed these 10 principles to support providers to deliver more appealing opportunities for disabled people.

**activity alliance**  
disability inclusion sport

## The 10 principles

During research published in our **Talk to me report**, disabled people told us:

### Principle 1

#### My channels

Use communication channels that I already trust e.g. social media, local media.



### Principle 2

#### My locality

Travelling to get to activities can be a significant barrier for disabled people. I would much prefer opportunities to be closer to home.



### Principle 3

#### Me, not my impairment

Many people do not identify with being disabled and are put off by advertising that focuses on disability.



### Principle 4

#### My values

Everyone has values. Understanding what my values are and linking an activity to these can make taking part more appealing.



### Principle 5

#### My life story

As people grow older our values change. Keep me interested over time through new ideas.



### Principle 6

#### Reassure me

Some disabled people fear standing out and need to be reassured that any activity we attend will be welcoming and suitable for our needs.



### Principle 7

#### Include me

Some disabled people need to know we are good enough to take part. Providers should make sure that people with varying ability levels feel included in sessions.



### Principle 8

#### Listen to me

Disabled people can be limited by our impairment and should be able to discuss our needs in a safe and private environment before starting an activity.



### Principle 9

#### Welcome me

An unpleasant first experience can prevent anyone from taking part again. Ensure my first experience is enjoyable so I'm likely to return.



### Principle 10

#### Show me

Engage disabled people who are already involved in your activity to promote it to others.



[activityalliance.org.uk](https://activityalliance.org.uk)



Figure 1. Activity Alliance's 10 Principles

### Activity Alliance: a catalyst for change

One of Activity Alliance's key functions is to collaborate with sports organisations, policymakers, and communities to develop and implement inclusive practices. As a charity, we provide guidance and support to ensure that facilities, programmes, and events are accessible to people of all abilities. By championing inclusive design, training, and awareness initiatives, Activity Alliance empowers organisations to embrace diversity and make sport and physical activity truly accessible to all.

Activity Alliance also acts as a catalyst for change by influencing policies and advocating for the rights of disabled individuals within the sports and physical activity landscape. Our '10 Principles' (Figure 1) are widely acknowledged by sport and leisure providers, supporting them to deliver more appealing and accessible opportunities for disabled people in conventional sport settings.

Our extensive resource packs include advice around using a mix of trusted communication channels and thinking carefully about the language used in promotions. Grouped into key areas, they ask providers to take into account

certain ideas such as 'include me', 'listen to me', 'welcome me' and 'show me'.

To see a shift in disabled people's activity levels major change is required. There are hundreds of organisations doing amazing work to break down barriers, and Activity Alliance will continue to lead the way, advocating for a future where everyone, regardless of ability, can embrace the transformative power of sports and physical activity.

### References

1. Activity Alliance Annual Survey Impairment Report. 2023. Available at: <https://www.activityalliance.org.uk/how-we-help/research/8436-activity-alliance-annual-survey-impairment-report-sept-2023> [Accessed Jan 24]
2. Get Out Get Active Impact Report. 2023. Available at: [http://www.getoutgetactive.co.uk/assets/000/001/134/26482\\_Activity\\_Alliance\\_GOGA\\_Impact\\_Report\\_Accessible\\_original.pdf?1703169224](http://www.getoutgetactive.co.uk/assets/000/001/134/26482_Activity_Alliance_GOGA_Impact_Report_Accessible_original.pdf?1703169224) [Accessed Jan 24]
3. Activity Alliance Annual Disability and Activity Survey. 2023. Available at: <https://www.activityalliance.org.uk/how-we-help/research/annual-survey> [Accessed Jan 24]
4. Activity Alliance My Active Future: Including every child. 2020. Available at: <https://www.activityalliance.org.uk/how-we-help/research/5658-my-active-future-including-every-child-march-2020> [Accessed Jan 24]

Find out more about the services  
*Activity Alliance* has to offer  
by scanning the QR code

**activity  
alliance**  
disability  
inclusion  
sport



# Nutrition and diet: supporting people with learning disabilities to make healthy choices

People with learning disabilities are more likely to have problems maintaining a healthy weight, which can have a significant impact on overall health and wellbeing. Family members, carers and other professionals can help to improve the nutritional status of the person they support with the right training and resources.

Eating a nutritious, well-balanced diet is a key component of living a healthy life – it can boost immunity, lower the risk of major diseases, and ultimately, help you live longer.<sup>1</sup>

However, people with learning disabilities, particularly those living in supported communities, tend to have poor diets with insufficient intake of fruit and vegetables, and they are also more likely to be overweight or obese.<sup>2</sup>

Given that people with learning disabilities die, on average, almost 20 years younger than the general population, nutritional programming should be high on the agenda for care givers and providers, yet it is often deprioritised.<sup>3</sup>

“Diet is often not explored enough in people with learning disabilities, and they are often given the choice to ‘choose’ very unhealthy foods on a regular basis,” explains learning

“Poor diets can leave people with learning disabilities at risk of experiencing “a wide range of social, health and wellbeing problems”

Lauren Nicolle, Editor, *In Focus*

disability nurse consultant and adviser, Jim Blair. “In my experience, many of these ‘choices’ are not real choices as the person may not understand the consequences of their ‘choice’.”

Blair says that says poor diets can leave people with learning disabilities at risk of experiencing “a wide range of social, health and wellbeing problems” which can lead to “restrictive, shorter lives.”

While an array of healthy eating resources have been produced in recent years, many of these resources lack necessary reasonable adjustments for people with learning disabilities. For this reason, Blair says there is still a “lack of information and materials for people with learning disabilities to gain a clear understanding about leading a healthy lifestyle and the vital role diet and exercise play.”

## Why are people with learning disabilities more likely to have poor dietary habits?

### Inherent causes

Sometimes, a poor diet is related to factors which are hard to control. For example, some people with learning disabilities have conditions which make it more difficult to eat and swallow (such as dysphagia), whereas autistic people may have sensory differences and routinised behaviours which can limit food intake.<sup>4</sup>

People with these conditions are more likely to become malnourished and underweight, which has led to increased rates of underweight in people with learning disabilities compared to the general population.<sup>5</sup>

Contrastingly, conditions such as Down’s syndrome and Prader-Willi syndrome can cause an insatiable appetite, while some psychotropic

and antiepileptic medications can induce weight gain.<sup>4</sup> It is therefore vital that people with these conditions are taught about the nutritional value of food to lower the risk of overweight and obesity.

## Lifestyle factors

There are also various social factors which can lead to poor nutritional intake, and Blair says there is a “lack of awareness” among staff supporting people in relation to health and the impacts of not having a balanced diet.

“Carers are not always aware of the issues and do not monitor the frequency of which someone is eating unhealthily and not exercising,” Blair says. This could be due to a lack of knowledge surrounding what constitutes a healthy diet, but the problem can be exacerbated when carers are time pressed.

Shopping for and preparing healthy meals can be time consuming, which can cause carers to become overly reliant on ready meals and takeaways, while some may use unhealthy snacks or activities (such as driving to a café or a pub) as a reward.

Furthermore, research shows that if family members, carers and other role models make unhealthy choices themselves, this can influence the people they care for, so they too need to be encouraged to portray healthy eating habits.<sup>6</sup>

A lack of availability and access to healthy foods can also be a key determinant of the nutritional status of people with learning disabilities.

Unhealthy foods are typically cheaper than healthier alternatives, with a recently published report finding that healthy foods are now twice as expensive than less healthy foods.<sup>7</sup> The report found that in 2023, healthier food cost more than £10 per 1,000 calories on average, in contrast to less healthy food which cost around £4.50.<sup>7</sup>

People with learning disabilities and caregivers therefore should be taught how to make affordable, healthy recipes to prevent them from turning to cheaper, less healthy options.

## Consequences of a poor diet

Poor dietary habits have led to higher rates of both obesity and malnutrition among people with learning disabilities compared to the general population.

### Case study: Dimensions' Nutrition and Wellbeing Project

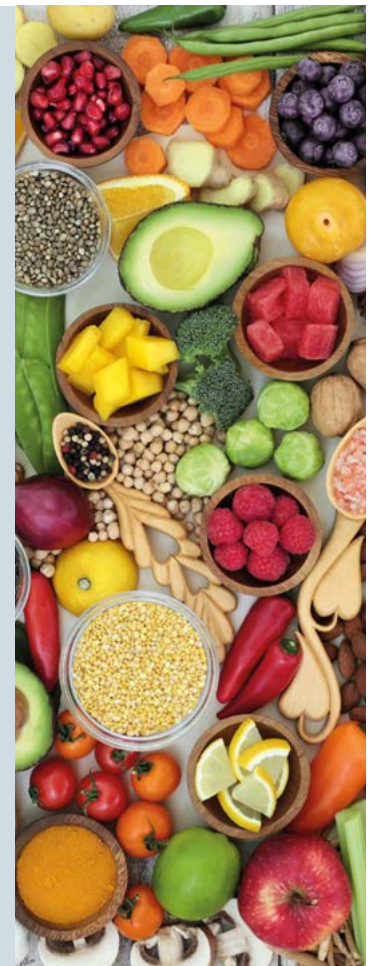
Dimensions launched its Nutrition and Wellbeing Project in 2020 to improve the health outcomes of people with learning disabilities. The project provides one-to-one coaching with menu plans and nutritional advice specifically tailored to individual preferences, empowering people with learning disabilities to maintain a healthy lifestyle and diet. Support workers are also trained to learn how to manage health conditions such as diabetes and heart disease through diet and exercise.

Paul Bown, Dimensions' Volunteer Officer who is responsible for co-ordination of the project, says he has seen the real-life benefits of the programme. “The project has been incredibly successful and is moving at a pace we were not initially expecting,” he said. “There’s been lots of interest both within Dimensions as well as among volunteers.”

Natasha, who Dimensions supports in Cardiff, lost two stone after starting the Nutrition and Wellbeing programme. The plan had three main goals: to drink two litres of water, eat five portions of fruit and vegetables and exercise for 30 minutes each day.

Nazmin, who developed Natasha’s programme, said: “It was really rewarding to see how effective this was for Natasha – she tells me that she feels better every day as a result of her weight loss.”

However, Nazmin says the biggest difference has been the impact on the staff. “Their knowledge and understanding have increased, and they feel that they can support Natasha and the other people in the house better. That’s a tremendous result.”





Public Health England estimates that 37% of people with learning disabilities are obese compared to 30% of the general population.<sup>8</sup> Being overweight or obese increases the risk of multiple major diseases, including coronary artery disease and strokes, type 2 diabetes, hypertension, obstructive sleep apnoea, osteoarthritis and some cancers (including breast, endometrial and colon).<sup>9</sup>

Conversely, 6.4% of people with a learning disability are classed as underweight, compared to 5% of the general population.<sup>5,10</sup> In people with learning disabilities, being chronically underweight may be mistakenly ascribed to the person's learning disability and accepted as part of their condition. However, the British Association of Dietitians warns that although being underweight is relatively common for people with learning disabilities, it is not normal and warrants intervention.<sup>4</sup> It is important to note that people who are overweight or obese can also be malnourished.

The consequences of being underweight include compromised immunity with increased susceptibility to infections, reduced respiratory function, decreased energy levels leading to reduced participation in daily activities and reduced overall quality of life.<sup>4</sup>

A poor diet can also lead to health complications such as constipation, which is estimated to occur in up to half (50%) of people with learning disabilities.<sup>11</sup> Constipation can be life threatening if it is not treated promptly and people with learning disabilities are more likely to have unusual presentations. They may also struggle to communicate their symptoms, both of which can lead to misdiagnosis and avoidable emergency admissions to hospitals.

When paired with an exercise regime, an adequate diet consisting of fruits, vegetables and wholegrains, all of which contain high levels

of fibre, can help to relieve constipation and prevent the complications.

### Could accessible cooking resources hold the solution?

Nutritional guides and cooking resources have been proven to be an effective tool in improving nutritional status, but reasonable adjustments will be required to ensure these resources are accessible to people with learning disabilities. One research project, published in *Nursing Times* and funded by Health Education England has shown how this can work in practice.<sup>12</sup>

The project developed two resources: an online recipe resource for people with learning disabilities, which includes videos showing each stage of the cooking process in real time, and a training programme which can be delivered to staff involved in the person's care.

The healthy recipes were all presented in an easy read format broken down into simple steps alongside the cooking videos. The videos also promoted safe cooking practices, such as hand washing and thoroughly cleaning utensils, as well as a special kitchen timer which used colours to indicate how much time had lapsed to indicate when the food was fully cooked. People with learning disabilities were involved in the creation of the recipes and were featured in the videos themselves.

The researchers also provided specialist training for NHS staff working in learning disability services, including nurses, psychiatrists, community support workers, physiotherapists, activity leads, safeguarding leads and home managers. The training focused on interventions such as behavioural nudges that can guide people's choices towards a healthier option, role modelling, positive reinforcement and repeated exposure to healthy eating habits.

For example, staff were taught to describe healthy foods with appetising terminology, encourage the use of smaller plates for food and bigger glasses for water, and put healthy foods at eye level, with unhealthy snacks placed at the back of kitchen cupboards or out of sight.

This research demonstrates the need to adjust usual ways of working in order to successfully foster healthy diet changes. Making reasonable adjustments is vital to ensuring people with learning disabilities, family members, paid carers and other professionals are able to successfully implement diet changes.

## Conclusion

Improving the diet and overall health of people with learning disabilities will require a holistic approach with multidisciplinary input. Government guidance states that weight loss interventions are more effective if supporters such as family carers or paid staff are included, but support from learning disability nurses, GPs and dietitians may also be required.<sup>8</sup> However, it is important that there is a consistent approach from every party.

“To change the narrative, carers and paid staff need to be given training regarding how to ensure effective choices regarding health and wellbeing,” says Blair. “Providing material and

resources for people with learning disabilities are vital to ensuring people with learning disabilities make the right choices regarding their health.”

However, these resources must be tailored to people with learning disabilities, with reasonable adjustments provided where necessary. Without these adjustments and positive role modelling from both family members and the professionals in their lives, it will be harder for people with learning disabilities to make positive, healthy changes in their diets and lifestyles.

Blair says ongoing monitoring from healthcare professionals is also a crucial step to achieve positive change, as well as ensuring people with learning disabilities have annual health checks and health action plans in place.

## Resources

- Kingston’s ‘Eating Well’ recipe guide: <https://canvas.kingston.ac.uk/courses/12067>
- Cookability (accessible video recipes): [https://www.youtube.com/watch?v=wZ\\_QwbAibBE&list=PLI79ZsuMB5bYbVZduF8\\_-jl\\_fPwpMqsCv](https://www.youtube.com/watch?v=wZ_QwbAibBE&list=PLI79ZsuMB5bYbVZduF8_-jl_fPwpMqsCv)
- Accessible Chef (easy read recipes): <https://accessiblechef.com/recipes/>
- Facts for Families: Food and nutrition: <https://dimensions-uk.org/wp-content/uploads/Facts-for-Families-Food-and-nutrition.pdf>
- Eating well: Nutritional and practical guidelines for children and adults with learning disabilities: <https://www.cwt.org.uk/wp-content/uploads/2015/02/EWLDGuidelines.pdf>
- Healthy Eating Healthy Living Pack: <https://www.sclcd.org.uk/healthy-eating-healthy-living-pack/>
- Healthy Eating: An easy-read booklet: <https://www.aceanglia.com/wp-content/uploads/2022/01/13.-Healthy-Eating-final-1.pdf>
- Managing weight with a learning disability: NHS England: <https://www.nhs.uk/live-well/healthy-weight/managing-your-weight/managing-weight-with-a-learning-disability/>
- Cooking with Friends by Sheila Hollins and Margaret Flynn: <https://booksbeyondwords.co.uk/bookshop/paperbacks/cooking-with-friends>
- How to keep your heart healthy: British Heart Foundation: <https://www.youtube.com/watch?v=tsvmoTPwgi4>

## References

1. Centers for Disease Control and Prevention. Benefits of Healthy Eating. 2021. Available at: <https://www.cdc.gov/nutrition/resources-publications/benefits-of-healthy-eating.html> [Accessed Jan 24]
2. Public Health England. Constipation: making reasonable adjustments. 2018. Available at: <https://www.gov.uk/government/publications/constipation-and-people-with-learning-disabilities/constipation-making-reasonable-adjustments> [Accessed Jan 24]
3. White, A; Sheehan, R. Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2022. LeDeR Autism and learning disability partnership, King’s College London. 2023.
4. Learning Disabilities Mortality Review (LeDeR) Programme: Fact Sheet 28. 2019. Available at: [https://www.bristol.ac.uk/media-library/sites/sps/leder/2103\\_Nutrition\\_PDF.pdf](https://www.bristol.ac.uk/media-library/sites/sps/leder/2103_Nutrition_PDF.pdf) [Accessed Jan 24].
5. Mencap. A Healthier Me. No date. Available at: <https://www.mencap.org.uk/healthierme>
6. Lippe, C. The Importance of Role Modelling With Food – Advice from a Nutritionist. Available at: <https://fennies.com/role-modelling-food/> [Accessed Jan 24]
7. The Food Foundation. The Broken Plate: The state of the Nation’s Food System. 2023. Available at: [https://foodfoundation.org.uk/sites/default/files/2023-10/TFF\\_The%20Broken%20Plate%202023\\_Digital\\_FINAL\\_.pdf](https://foodfoundation.org.uk/sites/default/files/2023-10/TFF_The%20Broken%20Plate%202023_Digital_FINAL_.pdf) [Accessed Jan 24]
8. Public Health England. Obesity and weight management for people with learning disabilities: guidance. 2020. Available at: <https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance> [Accessed Jan 24]
9. National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Health Risks of Overweight & Obesity. 2023. Available at: <https://www.niddk.nih.gov/health-information/weight-management/adult-overweight-obesity/health-risks> [Accessed Jan 24]
10. Saunders J, Smith T. Malnutrition: causes and consequences. *Clin Med (Lond)*. 2010 Dec;10(6):624-7. doi: 10.7861/clinmedicine.10-6-624.
11. Maslen C, Hodge R, et al. Constipation in autistic people and people with learning disabilities. *British Journal of General Practice*. 2022; 72 (720): 348-351.
12. Harper L, Ooms A. Developing dietary interventions for people with learning disabilities. *Nursing Times*. 2021. 117:4, 30-33.

# What matters to you?

## The importance of hobbies, interests and having fun

Since its inception in 2013, Stay Up Late has helped pair up thousands of people with learning disabilities with like-minded individuals. Here, Florence Little, Campaign Coordinator at Stay Up Late, explains why it is so vital that people with learning disabilities are able to pursue their hobbies and interests, and how this contributes to a happy, fulfilled life.

### Why fun matters

Everyone knows that exercise, eating well and getting enough sleep is good for you – we talk about it all the time. However, we don't often talk about the benefits of a good night out, especially not if you're an adult with a learning disability or an autistic person who might need a little extra support to get out there.

When we speak about disability rights, we understand the fundamental needs people have: the need for safe and secure housing, good health, and a fair education. Yet we ignore the more complex needs for belonging, socialising and growth.

At Stay Up Late, a small but mighty charity, we work to rectify this, reprioritising what makes care, and life, truly great. We fight for the right to party and support adults with learning disabilities and autistic people to have full and active social lives. We feel that a good night out, with music, dancing, and a tippie or three, is a great way to have fun. However, our main belief is that wherever you find it, fun is incredibly important.

People tend to agree that having a rich social life is beneficial, but it is often seen as a bonus in the lives of people with learning disabilities.

**Florence Little**, Campaign Coordinator, *Stay Up Late*

At Stay Up Late, we think it is absolutely integral. Friends, hobbies, and interests are some of the most important things to have in life and can impact our health in ways we've only just begun to understand.

Research tells us that isolation and loneliness can have a terrible impact, with one study suggesting that loneliness is worse for you than 15 cigarettes a day.<sup>1</sup> Being socially isolated can lead to problems with physical and mental health and can cause crises in care environments. Across our society, there's a loneliness pandemic, and some of the most affected are adults with learning disabilities and autistic people.

### “Us” and “them”

There is a history of institutionalisation in this country – for decades, people with learning disabilities were kept locked away in institutions under the pretence of care. Although most old institutions have closed their doors, we still live in a society which separates us, with people with learning disabilities placed in self-contained systems with their own schools, accommodations and even parties. This societal divide has created a general misunderstanding of disabled people and their lives.

Through our campaign work, we have encountered people brave enough to admit that they have never considered that someone with a learning disability might want to get drunk, or swear, or just be a regular human being. This is then reinforced by the lack of disabled representation within public spaces, which is misinterpreted as the norm.

Unless you are part of the disabled community, you might assume people with learning

disabilities and autistic people do not want to be out rather than realising how inaccessible and unwelcoming public spaces can be. This isn't intended to shame people, but it's important to recognise the general population's role within this exclusion.

People are surprised by the idea that adults with learning disabilities have the same desires to do the ordinary things they do themselves, and see no issue with a bar on a Friday night where no one is neurodiverse or disabled. The gap isn't ignored, it's invisible. If we overcame this bias, we'd recognise the lack of social opportunities for people with learning disabilities.

### Gig Buddies – a simple solution

Over the past decade, we have been working to change the narrative and bridge this societal gap. We believe segregation makes for a sterile environment where it's harder to introduce the same freedom of choice, opportunity, and joy which most of us take for granted. For many people with learning disabilities, the ability to go for an impromptu pint, pop to the shop or swing by a friend's house all must be decided or managed by someone else. These small joys are relatively ordinary, yet they have the power to reinvigorate people's lives.

We believe that a first step to reducing loneliness and social isolation is to focus on people's interests and passions as a way of reconnecting them with their wider communities. Making space for the things that may seem ordinary and taking time to recognise what really matters to people can make a huge difference to people's lives.

Stay Up Late began after our founder, Paul Richards, realised that very few people with learning disabilities were able to enjoy a night out without restrictions. Paul's band, Heavy Load, had five members, three of whom had learning disabilities. Yet his band members would often have to leave gigs early when their support workers finished their shift at 9pm. Paul wanted to see this change, and decided to start Stay Up Late, an awareness campaign which fought for the right to party.

---

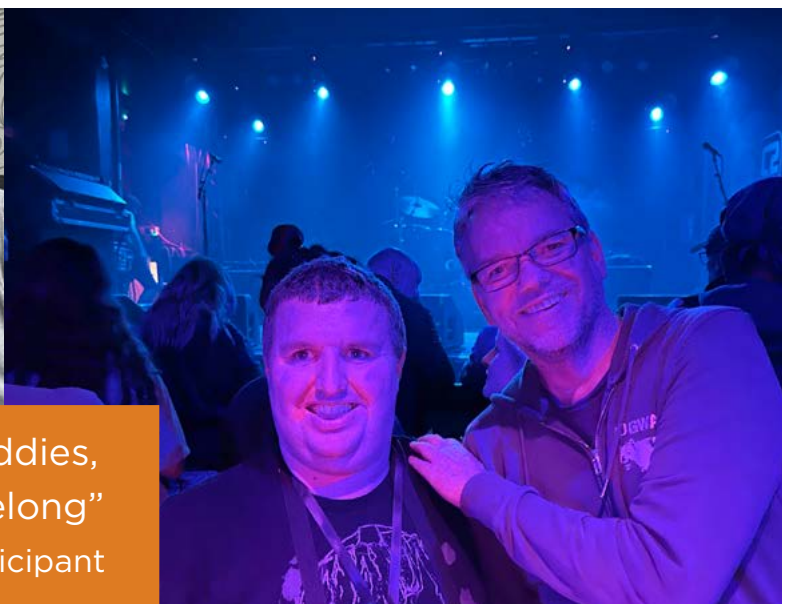
We believe that a first step to reducing loneliness and social isolation is to focus on people's interests and passions

---



In 2021, Heavy Load played their last ever gig, but thankfully, Paul had received the funding to start a new project which allowed people with learning disabilities to continue partying until the early hours of the morning. Enter Gig Buddies, our flagship project that pairs adults with learning disabilities and autistic people with volunteers based on their shared interests. We recognised that people could be from seemingly different lives but have a shared passion that connects them.

Gig Buddies, as the name implies, started with a clear link to music, pairing and mobilising likeminded individuals. However, over the years



“When I'm with Gig buddies, I feel like I'm where I belong”  
– Joseph, Gig Buddies participant

## Hobbies, interests and having fun

it has opened up to include more than just music. We realised that what brought people joy was too varied to be pinned down.

Gig Buddies has continued to grow and is now licensed across the world with 21 different projects in seven different countries (the furthest being New Zealand). And whilst each partner decides how best to serve its local community and create connections, a core facet continues to be people's ability to choose how they spend their time, defining what is valuable to them. We have many buddies who still go to gigs, but also cinema aficionados, gym buddies and even afternoon-tea goers. It's truly about whatever makes your heart sing.

“ As a charity, we want to be part of a joyful, inclusive society that respects people's interests and choices

Over the years we've seen the difference these friendships can make. From our most recent surveys, we found that 82% of participants feel less lonely since having a buddy, and 91% feel they have more control over their social life. This impact leads to lasting change and an increase in confidence that is truly magical to see.

For example, we have recently seen one of our members, 'Marcus' (not his real name), completely transform as a person after pairing

To find out more about Stay Up Late and their volunteering projects, please visit [stayuplate.org](https://stayuplate.org)



up with his buddy 'Nick'. Marcus had always been a relatively quiet and shy individual who felt nervous and unable to make friends or participate in large social groups. Within two months of being matched, Sophie, our Gig Buddies Coordinator who supports people's connection at the start of their journey, met Marcus for a social at the pub. Sophie said she barely recognised him. He was lounged on a sofa with a pint in his hand smiling and looking incredibly relaxed. He spent the evening talking to other buddies and joking with Nick.

### Creating a society that welcomes everyone

For me, the magic of Gig Buddies lies in its simplicity and the deeper changes it creates within people. What people gain from their newfound friendships is well worth our time and should be valued as such.

As a charity, we want to be part of a joyful, inclusive society that respects people's interests and choices, and we think that shifting our understanding of what matters in people's lives, regardless of disability, is a great place to start.

### References

1. The Guardian. WHO declares loneliness a 'global public health concern'. 2023. Available at: <https://www.theguardian.com/global-development/2023/nov/16/who-declares-loneliness-a-global-public-health-concern> [Accessed Jan 24]



**GIG  
BUDDIES**

**SPORTS  
BUDDIES**

**WHAT'S YOUR GIG?**

**WHAT'S YOUR MOVE?**

**VOLUNTEER AS A BUDDY**

**SHARE YOUR PASSIONS WITH SOMEONE**

**WITH A LEARNING DISABILITY**

**MAKE A NEW FRIEND**



**WWW.GIGBUDDIES.ORG.UK**

Gig Buddies and Sports Buddies matches up people with learning disabilities with a volunteer who shares the same interests in music, culture or getting active together.

# Sex, love and learning disability

Currently only 3% of people with a learning disability live as a couple, compared to 70% of the general adult population.<sup>1</sup> This article highlights the barriers to finding a partner and how, with the right support and education, people with learning disabilities can develop and maintain romantic relationships.

People with a learning disability have the right to develop loving relationships and express their sexual identity like everyone else. This is a vital element of living a fulfilled life, yet proactive support is essential in enabling people to develop and maintain these relationships.

“ Although some people with a learning disability may not be able to consent to having sex or a relationship, this is the minority

Common barriers to finding a relationship are not knowing how to meet a partner, a lack of social opportunities and finances, support staff issues, and a lack of autonomy. However, people with learning disabilities can be supported to develop a relationship with the help of family and staff support, particularly when they are given opportunities to learn about relationships and have access to specialist dating agencies.<sup>2</sup>

Other factors that can impact this group in navigating sex and relationships can include difficulties with understanding social cues and

**Alison Bloomer**, Editor, *Learning Disability Today*

rules, problem-solving social situations, and understanding what others might be thinking or feeling. They may also make literal interpretations of language leading to misinterpretations. Understanding emotions, both their own and others, can also be challenging.<sup>3</sup>

The unique needs of this group are also likely to impact how they process and recall the taught information in sex and relationships education.<sup>3</sup>

## Consent and capacity

Although some people with a learning disability may not be able to consent to having sex or a relationship, this is the minority, according to the learning disability charity Mencap.<sup>4</sup> In addition, the presence of a learning disability or a communication difficulty does not in itself imply incapacity.

The issue of capacity was recently examined in a landmark judgement delivered at the Supreme Court. It considered the concept of mental capacity and what “relevant information” a protected party should be able to understand, retain and use or weigh when assessing whether they have capacity to have sex.<sup>5</sup> ‘Capacity’ is whether someone is able to make their own decisions about something; ‘consent’ is whether someone who has capacity to decide something freely agrees to do it.

The Supreme Court confirmed that for a person to have capacity to consent to sex, they need to understand that their sexual partner must also have the capacity to consent to sex. Consenting to sexual activity must happen before the sexual activity starts and must continue throughout the sexual activity.

For care professionals, it will now be important to strike a balance between autonomy,

protecting vulnerable individuals, and the administration of justice.

This is why training for relevant staff is so important, as is the need to assess whether it is appropriate, depending upon each individual circumstance, to review previous capacity assessments conducted in relation to sexual relations.

A recent literature analysis found three key factors that had the potential to improve a person's ability to make informed decisions about sexual consent. These were education, attitude and advanced directive approaches.<sup>6</sup>

The authors concluded that approaches to sexual consent work best when they are person-centred. That is, the wishes of the person with a learning disability are understood and they themselves are involved in the process of personalising the approaches used to facilitate healthy intimate relationships.

The basic skill checks included:

- Knowledge of body parts and sexual relationships and acts
- Knowledge of consequences from sexual relationships
- Understanding of appropriate sexual behaviour and context for it
- Understanding of the voluntary nature of a sexual relationship
- Ability to recognise abusive situations
- Ability to be assertive in such situations to reject unwanted advances.

The authors added: "It is important for the attitudes of those involved in this process to be balanced; otherwise, the sexual rights of such assessed people could be moved either in favour or against them."

### Access to appropriate sex education

Mencap says that people with a learning disability often do not receive accessible sex education information and therefore may not have been taught about sexual health, contraception, LGBTQ relationships, masturbation, and the legal and emotional aspects of sex.<sup>3</sup>

Poor knowledge of sex and relationships can lead to people engaging in unsafe sexual practices, and lack of awareness to report sexual abuse.

Historically, sexual health has been ignored in people with learning disabilities and has only



discussed when there is a problem. Information should therefore be provided in a format suitable to their needs and should help them to make informed choices.<sup>7</sup>

This education also needs to be consistent in the various settings someone might be, and consistent between different people who might carry out a support role – family and carers, care workers, supported education or employment workers, and counsellors.<sup>7</sup>

---

LGBTQ people with a learning disability face 'double discrimination' because of their sexuality or gender

---



The Brandon Trust found that a lack of good guidance for support staff was a major barrier to enabling people to have sexual and romantic relationships, so they brought together managers, support staff, as well as the people they supported and their families, to create a new policy, guidance, and training around relationships, sex, and sexuality.

The guidance and training provides a wealth of practical information about what staff can and can't do, including information around mental capacity and consent, the law, and staying safe and healthy.<sup>8</sup>

### Same sex relationships

It is also important to recognise that people with a learning disability can be lesbian, gay, bisexual and transgender. As such, sex education



resources and campaigns for people with a learning disability should be designed with the specific needs of lesbian, gay or bisexual people in mind, rather than assuming that all people with a learning disability are straight (heterosexual).<sup>3</sup>

This is important as research has found that LGBTQ people with a learning disability face 'double discrimination' because of their sexuality or gender.<sup>9</sup>

### Exploitation and online risks

Research shows that individuals with disabilities are twice as likely to be the victim of sexual violence during their lifetime than the general population and women and children with learning disabilities can be up to four times more likely to experience sexual violence than people without a disability.<sup>10,11</sup>

Trying to protect the person with a learning disability from abuse or exploitation is one of the reasons why some support workers see their role as limited and report a lack of guidance on what they can and cannot do or say regarding supporting sexuality.<sup>3,8</sup>

A joint report by Voice UK, Mencap and Respond examined evidence and case studies which highlighted the type and extent of sexual abuse experienced by adults with a learning disability and how they are often poorly served by the legal system in England.<sup>12</sup>

It found that they were vulnerable to sexual abuse for a number of reasons, including:

- Having low self-esteem and therefore a lack of power within relationships
- Depending on care staff and care services for long periods
- Not possessing the social awareness or education to detect or anticipate abusive situations

- Being afraid to challenge potentially abusive situations. Many people with a learning disability have been taught not to question authority figures, and worry that the perpetrator will get angry or that they will get into trouble if they refuse
- Lacking the capacity to consent to sexual relations, as is the case for some people with a severe learning disability
- Being unable to recognise after the event that abuse has taken place
- Being afraid to report abuse after the event, although they recognise what has happened. Some people have communication difficulties, while others feel that nobody will believe them.

The report concluded that people with a learning disability have a right to a private life and to a life free from abuse. They should not be exposed to greater harm than the general population because of their disability. The authors said everything possible must be done to protect vulnerable people with a learning disability from abuse and respond to abuse when it does take place. The law must also be reformed to deter sexual abusers and existing loopholes must be closed to ensure that abusers are appropriately punished.<sup>12</sup>

As part of its Supported Loving Campaign, Choice Support has published resources on this issue.<sup>13</sup> It recommends professionals working with learning disabilities:

- Reassure the person that it is not their fault and they have done the right thing by speaking about sexual violence
- Ask the person if they want to tell the police. If it is a recent event, explain they may need to have a forensic examination
- Consider whether they are safe and what could be done to help facilitate safety
- Consider what local support services are available for this person
- Ask the person if they want counselling or therapy to process some of their feelings about what has happened.

There are also various resources on their website on a variety of issues surrounding learning disability, sex and relationships (see resource box).

### The future

According to research by the National Development Team for Inclusion (NDTi), people with learning disabilities want to have

relationships and it is an important part of their lives. However, unlike people without learning disabilities, institutional and attitudinal barriers prevent many people with learning disabilities from exercising and enjoying this fundamental human right.<sup>14</sup>

Often, they are not treated as adults who have the right to relationships by people around them. Sexuality is still a taboo subject, and family members, friends and carers may be overprotective. In addition, lack of knowledge and skills means some services do not give staff training on how to support people in intimate relationships.

Going forward, the NDTi recommends that clear guidance is developed for people with learning disabilities about their rights around intimate relationships. They also recommend that all good quality resources about intimate relationships and sexual health are collated and made accessible for people with learning disabilities.

The NDTi is now planning to work with organisations to review their policies, find out how they actually support people with intimate relationships, and come up with ways of improving this.

## References

- Emerson E, Hatton C. People with Learning Disabilities in England: CeDR Research Report 2008:1. Available at: [https://www.lancaster.ac.uk/staff/emerson/FASSWeb/Emerson\\_08\\_PWLDinEngland.pdf](https://www.lancaster.ac.uk/staff/emerson/FASSWeb/Emerson_08_PWLDinEngland.pdf) [Accessed Jan 24]
- National Institute for Health and Care Research. Love and relationships: the views of adults with learning disabilities. 2021. Available at: <https://evidence.nihr.ac.uk/alert/romantic-relationships-adults-with-learning-disabilities/> [Accessed Jan 24]
- Asagba, K. Sex and relationships education for people with intellectual disabilities and with autism. 2021. Available at: <https://www.learningdisabilitytoday.co.uk/topic/equality/sex-and-relationships-education-for-people-with-intellectual-disabilities-and-with-autism> [Accessed Jan 24]
- Mencap. Sexuality - research and statistic. N.D. Available at: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/sexuality-research-and-statistics> [Accessed Jan 24]
- A Local Authority (Respondent) v JB (by his Litigation Friend, the Official Solicitor) (Appellant) 2021. Available at: <https://www.supremecourt.uk/cases/docs/uksc-2020-0133-judgment.pdf> [Accessed Jan 24]
- Esmail S, Concannon B. Approaches to Determine and Manage Sexual Consent Abilities for People With Cognitive Disabilities: Systematic Review. *Interact J Med Res* 2022;11(1):e28137 doi: 10.2196/28137
- Sexual Health D&G. Let's talk about sex: learning difficulties. N.D. Available at: <https://sexualhealthdg.co.uk/learning-disability.php> [Accessed Jan 24]
- Brandon Trust. Love, sex, relationships, and learning disabilities. 2017. Available at: <https://www.brandontrust.org/whats-happening/news/love-sex-relationships-and-learning-disabilities/> [Accessed Jan 24]
- Wilson N, Macdonald J, Hayman B, et al. A narrative review of the literature about people with intellectual disability who identify as lesbian, gay, bisexual, transgender, intersex or questioning. *Journal of Intellectual Disabilities* 2016; 22(2), 171-196.
- Mailhot Amborski A, Bussi eres EL, Vaillancourt-Morel MP, Joyal, CC. Sexual Violence Against Persons With Disabilities: A Meta-Analysis. *Trauma, Violence, & Abuse* 2022; 23(4), 1330-1343. <https://doi.org/10.1177/1524838021995975>
- Sitter K, Burke A, Ladhani S, Mally N. (2019). Supporting positive sexual health for persons with developmental disabilities: Stories about the right to love. *British Journal of Learning Disabilities*, 47(4), 255-263.
- Mencap, Respond, Voice UK. Behind closed doors. Preventing sexual abuse against adults with a learning disability. 2001. Available at: [https://lx.iriss.org.uk/sites/default/files/resources/behind\\_closed\\_doors.pdf](https://lx.iriss.org.uk/sites/default/files/resources/behind_closed_doors.pdf) [Accessed Jan 24]
- Choice Support. Supported Loving toolkit. Sexual violence. N.D. Available at: <https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving/supported-loving-toolkit/sexual-violence> [Accessed Jan 24]
- NDTi. The right to a relationship. 2019. Available at: <https://www.ndti.org.uk/resources/the-right-to-a-relationship> [Accessed Jan 24]

## Resources

- Josephine and Jack Project: [www.josephineandjackproject.co.uk/](http://www.josephineandjackproject.co.uk/)
- Brandon Trust: [https://www.brandontrust.org/old\\_media/313124/brandon-trust-easy-read-relationships-sex-and-sexuality.pdf](https://www.brandontrust.org/old_media/313124/brandon-trust-easy-read-relationships-sex-and-sexuality.pdf)
- Choice Support: Supported Loving: <https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving>
- Supported Loving: Friendship and dating agencies: [www.choicesupport.org.uk/about-us/what-we-do/supported-loving/supported-loving-toolkit/dating-and-friendship-agencies](http://www.choicesupport.org.uk/about-us/what-we-do/supported-loving/supported-loving-toolkit/dating-and-friendship-agencies)
- You Being You: [www.mencap.org.uk/advice-and-support/relationships-and-sex/relationships-and-sex-resources](http://www.mencap.org.uk/advice-and-support/relationships-and-sex/relationships-and-sex-resources)
- Sex and Relationships Education for Young People and Adults with Intellectual Disabilities and Autism: [https://www.pavpub.com/app/uploads/2019/03/SexRelationshipsEd\\_SAMPLE.pdf](https://www.pavpub.com/app/uploads/2019/03/SexRelationshipsEd_SAMPLE.pdf)

# Empowering people with learning disabilities to gain employment

**N**early nine in 10 unemployed people with a learning disability say they want a paid job, yet only 5% are in paid employment. This gap, known as the learning disability employment gap, exists for a myriad of reasons, including a lack of understanding from employers and inaccessible processes. Here, the employment team at the learning disability charity Mencap explain how they support people with learning disabilities to gain meaningful employment.

## Employment Team, *Mencap*

Mencap research has found that as many as 86% of people with a learning disability not currently in work would like a job, but many face barriers such as inaccessible application forms and a lack of understanding from employers about their capabilities or where they might need additional support.

Even when people with a learning disability have secured a job, employers do not always allow them extra time or support to perform their duties, causing many to leave.

## Case study: Niaz

Niaz Taghavi from Barnet, North London, is autistic and has a learning disability. Despite his enthusiasm and hunger to work, it took him more than 60 job applications before he landed a job as a retail assistant at Curry's in September 2023.

He was helped by Bright Futures, an employment project run by Barnet Mencap and Royal Mencap. The project helped him at weekly job clubs where he had support in using job-searching sites, writing his CV, and role-playing job interviews, as well as engaging in peer-to-peer support with his fellow job seekers; all of whom have a learning disability or autism.

Niaz said: "Before the pandemic, my health struggles led to a lack of confidence and difficulty finding employment. My mother reached out to Mencap, and that's when my journey with Employ Me began.

"The support plan they crafted addressed my employment needs, including writing a CV, applying for essential passes, and finding stable housing. They focused on my mental health, crucial for engaging me in the job application process.

"The result was multiple interview offers, with the Employ Me team providing unwavering support throughout. Addressing the support around me, especially concerning mental health, was the turning point. Engaging in the job application process became possible because of the holistic support provided."

Niaz says getting a job at Curry's has made a huge difference to his life, opening doors to greater financial freedom, independence, self-confidence and new skills. He is now a star employee!

"I've met a lot of people at Curry's; the managers are lovely and super supportive, and I've made some friends - sometimes we have pizzas and deserts with my team. Since joining I've sold a £5,000 TV; my manager was so happy with me and gave me a handshake to say well done. The money I've earned helped me buy a gaming keyboard and video games as well as save for the future.

"I have an amazing support system at Curry's; I feel so respected, and I like they don't care what I look like or my disability. They know how to help me."

Zeeshan Sharif is a Mencap case worker who supports people with a learning disability to get into employment. So far, he has helped 27 people to get a job.

Zeeshan said: "At Mencap, we are campaigning for employers to do more to attract people with a learning disability into the workplace and to help them thrive, and we offer employment support through one-to-one and group sessions. We advise on everything from how to search for a job to how to write a CV, as well as offering interview practice. We also support with internships to help people get valuable work experience and provide easy-read career advice guides.

"Just like the rest of society, people living with disabilities have the right to have a career, earn their own money and live out their passions, and at Mencap, we will do everything we can to help with this."

This article features two cases studies which highlight what it means for people with learning disabilities to gain employment, as well as information on how to get help and support from Mencap's employment team.

## Case study: Andrew

Andrew Self, 27, from Surrey, had ambitions to be a hairdresser, but was having difficulty getting work after his supported internship at a local salon came to an end. His mum Donna, 60, suggested they try a less conventional route, posting on their local Facebook pages to see if any hairdressers in the area were looking for an assistant.

To Andrew's delight, the post was shared over 700 times and caught the attention of Lisa Philips who owns Ora Hair in Banstead. She offered Andrew a trial and then part-time employment of four hours each week spread across two afternoon shifts. Lisa and the team offered Andrew additional support to ensure he'd succeed in his new role, providing visual aids to help prompt and remind him of each task he needs to complete.

Since then, Andrew has delighted customers with his singing and dancing on the shopfloor, proving himself a total asset to the business. He's also become a Myth Buster for the Mencap, challenging misconceptions about what people with a learning disability can do.

Andrew said: "When I got the job, I was very excited and very happy! I've learnt to use the coffee machine, I sweep hair, clean the chairs and bases, fold the towels, hand the foils to the stylists and take drinks and biscuits to the customers and put their gowns on. The customers are all lovely and kind, and the staff are very supportive - it is very important because I feel safe and wanted."

### Mencap's top tips for getting a job

- 1. Get support** - There are many people able to offer support with getting employment, such as job centre staff or social workers. Mencap has a number of programmes which offer one to one support and weekly jobs clubs. People are taught everything from how to search for a job, write a CV, and perform in an interview. They're also helped once they gain employment with resilience, communication skills and travel training.
- 2. Get experience** - Taking on voluntary work or work experience can be a great way to learn about a job you might like to do and try a job for a short amount of time, as well as helping to find new friends and new skills. It is also a good way to get a reference which will help when applying for a paid job. You could even think about volunteering in a Mencap charity shop.
- 3. Understand how work might affect your benefits** - Research shows that some people with a learning disability are deterred from working because they worry about it affecting their benefits. Volunteering and work experience don't affect people's benefits, but if you are in doubt, you can contact Mencap for advice or speak to your job centre advisor.

*\*Please visit the 'Employ Me' section of Mencap's website or call 0808 808 1111 to access employment support.*

### Key facts:

- Research shows people with learning disabilities stay in their jobs longer than their non-disabled co-workers.
- In a large study, 92% of consumers interviewed said they felt more favourable towards companies that hired people with disabilities, with 87% specifically agreeing that they would prefer to give their business to companies that hire people with disabilities.
- Team dynamics and overall performance have been known to improve as a result of employing someone with a learning disability.

**Source: Mencap**

# Is living a good life still a pipe dream for people with a learning disability?

**W**hat if people with learning disabilities could push for real societal change and be seen and accepted as equal citizens in their communities and in media and politics? The 'Good Lives' framework from Learning Disability England aims to do exactly that.

As CEO of a social care provider having recently gone through the budget setting period, I know only too well that times are tough. The importance of investing in quality support and ensuring the workforce are paid as much as can possibly be afforded are very high on the priority list, and all other costs get close scrutiny.

At SeeAbility, we're members of various organisations, all of which have to be good value for money and ensure our membership helps us to achieve our aims. Membership at Learning Disability England (LDE), to us, is critical. Why? Well, this is about being part of something bigger than us: this is about a movement for change.

“ . . . if we work together, I believe we'll get closer to achieving these aims than ever before ”

We all know that many people still aren't living the lives they choose, that people don't have the rights, choice, inclusion, and independence that we all expect, and that active citizenship is still a pipe dream for many people with learning disabilities. Yet, if we work together,

**Lisa Hopkins, CEO, SeeAbility**

I believe we'll get closer to achieving these aims than ever before.

## **The 'Good Lives' project**

LDE is the only national membership organisation that brings together members with learning disabilities, families, professionals and organisations. It believes that societal change will happen when people with learning disabilities are seen and accepted as equal citizens in their communities and in media and politics.

The unique thing about LDE is who runs it. LDE's Representative Body is made up of self-advocates, families, and professionals. It's the strength of their collective voice that I believe will change things for the better and will create the difference we're all desperate to see.

I've lived in England now for 15 years. Through my work in social care, I have seen countless papers, frameworks, guidelines, standards and manifestos pass over my desk. It's exhausting thinking about them and how little has really changed as a result. But LDE are doing something different.

'The Good Lives: Building Change Together' framework has been co-produced through real collaborative working by people with learning disabilities, their friends, families, and paid supporters.

The framework brings together people's thoughts and ideas about what it will take for everyone with learning disabilities to be able to live their good life. It is there for anyone who is interested. LDE host the framework, but they do not control it - it belongs to the community.

It is not an end point. It is not a report. It is a framework to start a debate and give ideas for action.



... societal change will happen when people with learning disabilities are seen and accepted as equal citizens



*"Hurrah for change! Hurrah for more good lives! Hurrah for LDE!"*

*"I believe the good lives plan is a great way of showing how people can have a good life and show partnership working. This shows how LDE brings all of its members together and creates a bigger voice which is needed more than ever."*

*"I really hope this is our time and that everything changes so that we all have a good life."*

And what's the learning from all of those failed papers in the past? That small steps matter, no one needs permission to start to take action, and that together, we are stronger.

And that, in short, is why I'm both a personal member of LDE and an organisational member, and it's why I urge you all to engage with Good Lives.

### How can we use the Good Lives framework in practice?

At SeeAbility, we're starting to use the Good Lives framework in a number of ways:

- It has given us some ideas for action and we're working with people we support to use it as part of our own quality of life strategy.
- We are using it to shape our auditing tool to help identify whether people we're here to serve are living a Good Life.
- We are borrowing ideas of excellence from elsewhere so that we can get better in all that we do.

People with learning disabilities, who we support or are colleagues, have also commented on the new framework. They said:

This stuff is important. In fact, at the moment, it's easy to argue that it's critical. Together, we are stronger.

LDE host the framework, but they do not control it - it belongs to the community



**For more information on the Good Lives project, please visit: <https://www.learningdisabilityengland.org.uk/welcome/our-work-good-lives/>**

# Healthy ageing and Down's syndrome

**T**here is evidence to suggest that some biological problems related to ageing can occur earlier in people with Down's syndrome than in the general population; this is known as 'accelerated ageing'. People with Down's syndrome may therefore need extra health checks to ensure they live healthy lives for as long as possible.

Life expectancy estimates for adults with Down's syndrome have increased in recent decades. This mirrors the improved access to medical treatment for those with a learning disability, and a shift in public attitudes during the past 20 to 30 years that has resulted in better care within the community.<sup>1</sup> Improved surgical repair of congenital heart defects have also had an impact.

“ People with Down's syndrome are at risk of “accelerated ageing”

Yet, people with Down's syndrome are at risk of “accelerated ageing” such as early-onset dementia, early-onset menopause, hearing and visual impairments, and musculoskeletal problems. By the time they reach the age of 45 years they can be considered as “old”.<sup>2</sup> Many family members and caregivers commonly observe that people with Down's syndrome appear to “slow down” once they enter their late 40s or 50s.<sup>3</sup>

This article discusses some of the more common health issues in people with Down's

**Alison Bloomer**, Editor, *Learning Disability Today*

syndrome as well as the prevention and treatment measures available that can reduce the risk of long-term illnesses and increase quality of life.

It is important that family carers are well informed of health issues in advancing age so decisions can be made about health management.

## Annual health check

Anyone who has a learning disability and is aged over 14 years should have an annual health check with their GP. Annual health checks can identify undetected health conditions early, ensure the appropriateness of ongoing treatments, and establish trust and continuity care with the medical profession.

The Royal College of General Practice (RCGP) together with NHS England have produced a



toolkit with guidance and resources to help GPs, practice nurses and their wider team to organise and perform quality annual health checks on people with a learning disability.<sup>4</sup>

It has a syndrome specific guide for Down's syndrome which focuses on eyesight and hearing, feeding, bowel and bladder function, behavioural problems and decline in skills.

Mencap also have an easy read guide on what to expect from a health check.<sup>5</sup>

### **Down's syndrome and Alzheimer's disease**

It is well documented that adults with Down's syndrome are at higher risk of Alzheimer's disease. This could be because of an extra copy of the amyloid-precursor protein (APP) gene located on chromosome 21.<sup>6</sup>

The US National Down Syndrome Society (NDSS) say that most adults with Down's syndrome will not self-report concerns about memory.<sup>3</sup> Instead, it will take an astute caregiver who knows the individual well to identify early changes or concerns and bring them to the attention of a medical professional.

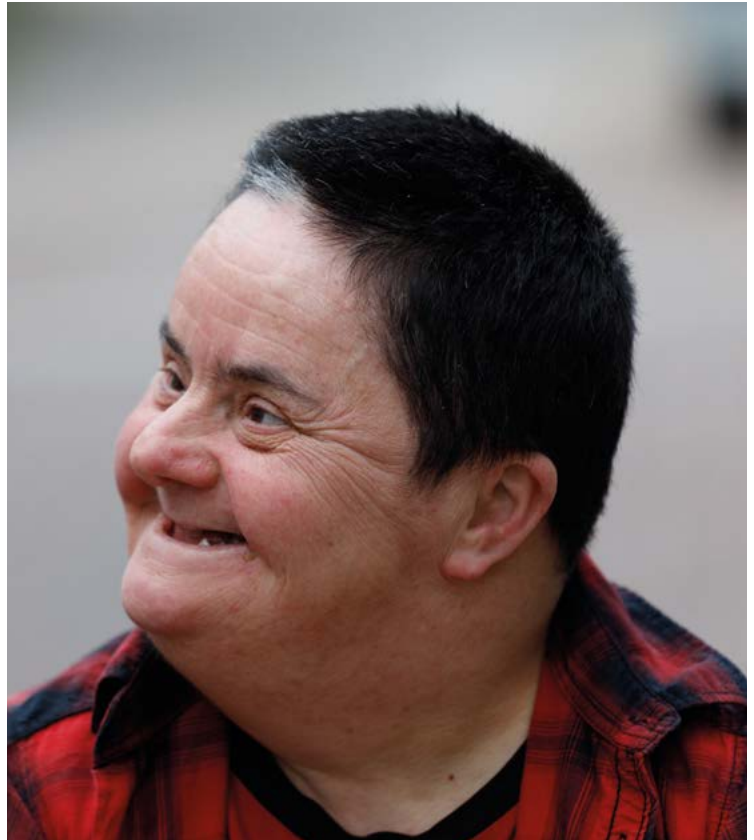
It adds that Alzheimer's disease is not inevitable in people with Down's syndrome. While all people with Down's syndrome are at risk, many adults will not manifest the changes of Alzheimer's disease in their lifetime.

In addition, research from the Down's Syndrome Resource Foundation has found that a healthy lifestyle can help the brain function more optimally and reduce the impact that genetics have on developing the disease.<sup>7</sup>

Elizabeth Head and Frederick Schmitt from the University of Kentucky said that a diet rich in fruits and vegetables that contain lots of antioxidants is associated with a reduced risk of developing Alzheimer's disease. They also said that evidence suggests that a Mediterranean diet (including foods like fruits, vegetables, nuts and grains) also appears to lower risk of disease.

A healthy diet may be particularly beneficial for people with Down's syndrome as several genes on chromosome 21 can lead to higher levels of oxidative stress in the brain, which is modifiable with a diet rich in antioxidants.

They added that physical exercise is another lifestyle habit that can lead to vast benefits



---

### A healthy diet may be particularly beneficial for people with Down's syndrome

---



both for the heart and for the brain, especially as a recent study suggested that extra weight in midlife may lead to an earlier age of onset of Alzheimer's disease.<sup>8</sup>

Obesity is widespread in people with Down's syndrome (89-95%), likely due to lower activity levels and a lower metabolic rate, making exercise and energy restriction critical in maintaining a healthy weight.<sup>9</sup> Walking, running, playing sports, dancing and strength training all come with significant benefits to brain health.

### **Obstructive sleep apnoea**

At least one third of people with Down's syndrome have obstructive sleep apnoea (OSA), which may be due to a small jaw and upper airways combined with macroglossia, as well as blocked nose and most of all obesity.<sup>9</sup> OSA can occur at any age and cause daytime sleepiness, behavioural change, loss of skills and other symptoms suggestive of depression or dementia.

The RCGP guide says that management should include an Epworth sleepiness score and referral for sleep studies.<sup>4</sup> Weight loss, if obese, as well as a continuous positive airway pressure (CPAP) mask overnight can dramatically improve the symptoms of OSA and the wellbeing of patients.

“ As adults with Down's syndrome grow older, there is increased risk of experiencing certain common mental health disorders

The main symptoms to look out for, according to the Down's Syndrome Association (DSA), are history of loud snoring combined with restless sleep, gasping noises when sleeping, drowsiness during the day, behaviour changes, poor concentration and irritability.<sup>10</sup>

### **Mental health problems**

As adults with Down's syndrome grow older, there is increased risk of experiencing certain common mental health disorders like depression, anxiety, obsessive compulsive disorder and behavioural disturbances.<sup>3</sup>

In its Getting Older guide, the DSA say that there is evidence that people with Down's syndrome may be more prone to depression than the general population.<sup>10</sup> The reasons can be multitude including the impact of events in their lives, such as past abuse or recent bereavement.

It says severe depression is initially best treated usually through the use of the newer anti-depressant medications. However, it is also important to deal with any other major issues in a person's life, such as the quality of the environment or bereavement. The effects of these changes should not be underestimated as individuals may experience great difficulty coping.

The RCGP guide says discriminating depression from dementia can also be difficult but is important, since the former is amenable to medical therapy.<sup>4</sup> Symptoms more suggestive of depression include withdrawal and decreased appetite and speech.

### **Hypothyroidism**

Hyperthyroidism in people with Down's syndrome is also more common than in the general population - it affects 15-37%, with the prevalence increasing with age. The development of under-activity of the thyroid gland can occur slowly and go unnoticed.<sup>9</sup>



The key changes that should lead to a suspicion that someone may have hypothyroidism are dry skin, brittle hair, general mental and physical slowing, increased intolerance of cold and unexplained weight increase.

Thyroid dysfunction is easily detected via a screening blood test and thyroid medication is prescribed to regulate abnormal hormone levels.

## Menopause

Women with Down's syndrome have an earlier menopause around 44 years on average. According to the DSA, the emotional symptoms of the menopause are often dismissed as challenging behaviour caused by the woman's learning disability, rather than being correctly diagnosed.<sup>10</sup>

This difficulty can be compounded by the fact that women with Down's syndrome often have problems describing their symptoms. They are often not aware of a "hot flush"; being unable to tell the difference between a flush and feeling hot due to the weather, for example.

Early onset of the menopause is often associated with osteoporosis. Down's syndrome is already an independent risk factor for osteoporosis, further increased by early menopause, anti-epileptic medication and other risk factors, so there is an increased fracture risk in women over the age of 50 years.

Often there are no symptoms of osteoporosis, but sometimes there may be a change in the way a person walks. If osteoporosis is suspected, a bone density test may be carried out.<sup>10</sup>

## Planning for the future

As well as recognising and treating health issues, a person with Down's syndrome will face many life changes as they get older, including retirement, loss of parents or other carers, and moving from home. That is why it is important to get support to plan for the future.

This could include avoiding a potential crisis situation created by illness or death of a carer, or ensuring continued access with the community after retirement.

Maintaining sources of enrichment, pleasure and stimulation are critical for individuals with Down's syndrome and will not only improve quality of life but also physical health and mental wellbeing.

## Resources

- Getting older: Down's Syndrome Association: <https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/ageing-and-dementia/>
- Mencap: Annual Health Checks: <https://www.mencap.org.uk/advice-and-support/health/dont-miss-out/dont-miss-out-annual-health-checks>
- National Down Syndrome Society: Aging and Down Syndrome: [https://ndss.org/sites/default/files/2022-06/Aging-and-Down-Syndrome\\_0.pdf](https://ndss.org/sites/default/files/2022-06/Aging-and-Down-Syndrome_0.pdf)

## References

1. Bittles AH, Glasson EJ. Clinical, social, and ethical implications of changing life expectancy in Down syndrome. *Dev Med Child Neurol*. 2004 Apr;46(4):282-6. doi: 10.1017/s0012162204000441.
2. Covelli V, Guastfiorro E, Leonardi M. (2020) Daily Life and Planning for the Future of Ageing People with Down Syndrome: Results from a National Study on Caregivers. *Advances in Aging Research*, 9, 95-115. doi: 10.4236/aar.2020.96008
3. National Down Syndrome Society. Aging and Down Syndrome. A Health & Wellbeing Guidebook. Available at: [https://ndss.org/sites/default/files/2022-06/Aging-and-Down-Syndrome\\_0.pdf](https://ndss.org/sites/default/files/2022-06/Aging-and-Down-Syndrome_0.pdf) [Accessed Jan 24]
4. Royal College of General Practitioners. Step-by-step guide to Health Checks for people with a learning disability. Available at: <https://dimensions-uk.org/wp-content/uploads/GP-Health-check-Step-by-Step-Guide-to-LDAHCS.pdf> [Accessed Jan 24]
5. Mencap. Annual health checks. Available at: <https://www.mencap.org.uk/advice-and-support/health/dont-miss-out/dont-miss-out-annual-health-checks> [Accessed Jan 24]
6. Alzheimer's Society. Understanding what causes the increased risk of Alzheimer's disease in Down's syndrome. Available at: <https://www.alzheimers.org.uk/understanding-what-causes-increased-risk-alzheimers-disease-downs-syndrome> [Accessed Jan 24]
7. Down Syndrome Resource Foundation. Alzheimer's Disease. Available at: <https://www.dsrf.org/resources/information/health-and-medical/alzheimers-disease/> [Accessed Jan 24]
8. Chuang YF, An Y, Bilgel M, Wong DF et al. Midlife adiposity predicts earlier onset of Alzheimer's dementia, neuropathology and presymptomatic cerebral amyloid accumulation. *Mol Psychiatry*. 2015.
9. Barnet Hospital and Community Services, Royal Free London NHS Foundation Trust. Combined Care Pathway for Children and Young People With Down Syndrome. 2020. Available at: [https://www.dsmig.org.uk/wp-content/uploads/2021/11/Down\\_Syndrome\\_combined\\_care\\_pathway\\_final\\_V3\\_Dec\\_2020\\_8.pdf](https://www.dsmig.org.uk/wp-content/uploads/2021/11/Down_Syndrome_combined_care_pathway_final_V3_Dec_2020_8.pdf) [Accessed Jan 24]
10. Down Syndrome Association. Getting Older. Available at: <https://www.downs-syndrome.org.uk/wp-content/uploads/2020/06/Ageing-Final-Format-5th-April-DSMIG.pdf> [Accessed Jan 24]

# Sign up to

# in **Focus** **ldt**

# today

and get your  
**first four issues for £20**



Each issue of *In Focus* acts as a resource pack for those involved in the care of people with learning disabilities. Forthcoming editions will cover:

- Transitioning to adult services
- Housing
- Employment
- Healthcare

Sign up by 31st March 2024\* to save £5 using coupon code

**LDTINF5**

\**In Focus* will cost £25 per year from 1 April 2024.

Sign up here

[www.learningdisabilitytoday.co.uk/  
account/register/](http://www.learningdisabilitytoday.co.uk/account/register/)

