



Anthony Collins

dimensions

ambient  
Passionate About People

Look Ahead  
CARE, SUPPORT AND HOUSING

Choice Support

SEE ABILITY  
Live. Love. Thrive. Belong.

M  
MacIntyre  
Providing support...your way

Official Conference Newspaper

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# Action Towards Good Lives

## Welcome to Learning Disability England's 2023 conferences



One of the last events we ran in 2020 before going into lockdown was our first meeting to talk about Good Lives.

We are really pleased that so many of you are joining us for our first in-person conferences since then, to be part of bringing Good Lives to life through action.

This year the conference looks a bit different, with online sessions and dates in London and York. We hope this will give everyone a chance to get involved.

We hope this conference will bring everyone together in showing what actions people and organisations are taking as well as inspiring others.

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# Stronger, Louder, Together!



Achieve together

# The Beauty of Sleep

‘Did you sleep alright?’ How many times have you heard or asked this question?

Why do we repeatedly check if we have had a good night’s sleep? Possibly we value having good quality sleep but at times it is difficult to achieve.



Sleep is an important aspect of our lives, the quality of our sleep can have a positive or negative effect on our mental and physical wellbeing. Adults need between 7 to 9 hours of sleep per night, to maintain good wellbeing. Many people sleep more or less, and there are many reasons for this.

Despite sleep being an important part of life, taking up about a third of each day, little attention and research is focused on any particular difficulties with sleep that people with learning disabilities face.

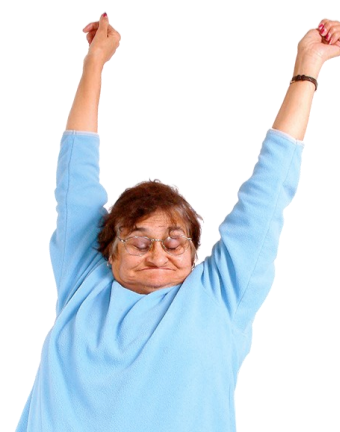
Sleep difficulties, including sleep disordered breathing (such as sleep

apnoea) and insomnia, are more common for adults with learning disabilities compared to the general population, sometimes with people experiencing multiple sleep difficulties. This can also impact on family for those people who need support day and night.

Nationally there needs to be more support, offering people easier and better access to sleep specialists, particularly when a person with learning disabilities has multiple reasons for having disturbed sleep. GPs and other local health professionals may not have the relevant skill and experience to recommend effective strategies to manage sleep difficulties, and this could result in making the problem worse. Let’s all pay more attention to the quality of our sleep, and argue for more specialist support locally for people who have long term sleep issues which are affecting their physical and mental health.

And on that note, sleep well tonight!

Find out more about Achieve together and Campaign 4 Change:





# Using Good Lives as an Organisation

The Ambient Guardians are a group of experts by experience who use their skills and knowledge to speak up for their peers and help Ambient Support to improve the quality of support they provide.



In summer 2022, 16 Guardian members met to look at Good Lives. They used Good Lives to guide their conversation and think about what was important to them in having a fulfilling life. They thought about how Ambient supports them and Good Lives helped them to assess if and how things could be done differently. The Guardians made recommendations for improvements to Ambient’s Quality Group and the Board of Trustees.

Communication was one theme the Guardians wanted to work on. They wanted to make sure everyone received information in the right way for them. They felt Ambient needed to do more to tailor communication to meet the needs of everyone they support to make sure it was accessible and understood.

The following changes were made within Ambient as a result of the Guardians work:

- The Guardians made an resource pack for staff on creating easy read. This was shared with the Quality Group and wider support staff to help everyone understand how to make good quality easy read and why it is important.
- Minutes from involvement meetings are now available in easy read, audio and video recordings.
- Staff have been working with people on how they prefer to be contacted and receive information. They are using things like facetime video calls, audio messages and WhatsApp.

All of these ideas from the Guardians have made it much easier to feel connected and confident in knowing what is happening at Ambient as well as getting involved.

Good Lives has been a great tool to help Ambient think about how we improve our support services. We greatly value the opportunity it provides for us to benchmark and make a positive impact on the lives of those we support.





# Our year as a Representative Body

**The Representative Body is the group of Learning Disability England members who are elected to steer our work. We represent and work with members to make a difference. We make important decisions about what Learning Disability England says and does and check it is staying true to its values.**

The Rep Body is made up of 12 people in total, with 4 self-advocate reps, 4 families and friends reps and 4 paid supporter reps.

We were really pleased so many members voted in last years election and our new Rep Body members have been settling into their roles.

The Rep Body meets four times a year to talk about what we are hearing from members. A small group of us act as Co-Chairs to help make decisions between meetings. At the moment the Co-Chairs are Jack, Kate, Tim and Scott.

We have three big things we are working on next. First, we are working for Good Lives and taking action or influencing to get the change that we all want. We want to keep sharing the Action Towards Good Lives so we can all learn about what is working in different areas or in some people's life.

Second, we will be looking for new people to join our board of Trustees. More information will be coming soon, keep on eye on the newsletter!

Finally, we will also be looking at how Rep Body elections work, we have held two elections and have learnt a lot. We want to consult with you as members to make sure we are running elections the best we can.

## **We want to hear from you!**

As member reps we want to hear from members about what's important to you. We would love to hear about what you are doing to make good lives happen.

You can meet us at a Members and Reps session, we are holding these twice a year. Keep an eye on the newsletter for the next session dates.

We are looking forward to speaking with you at this years' conferences, if you spot us do come over and say hello!

Or you can contact us via [info@LDEngland.org.uk](mailto:info@LDEngland.org.uk)

Find out more about your reps:



Our final handover meeting between the new and old rep body members in October 2022.



# Good Lives Actions

Its been a year since we launched Good Lives. It has been wonderful to have so many people thinking about it, using it in their work and giving us feedback. We know of over 50 events where Good Lives has been shared and we have met with 34 member organisations to share it with their teams.



Social movements like #SocialCareFutures and other umbrella organisations like Local Government Association have offered their support, writing about how Good Lives fits with their work.

Good Lives hasn't been about starting something new but bringing the work everyone is already doing together to achieve our shared vision for a good life. We want Good Lives to be a way of capturing that action and helping grow momentum by making sure others around the country know what's happening and can offer their support.

One of Learning Disability England's core jobs in supporting Good Lives is helping to share these actions and their impact. One way we are doing this is through a Good Lives Action Bank which is hosted on our website. This is an area for people to share stories, case studies, resources, and their wins in how they are helping move us towards Good Lives. We hope you will share some of your work as part of the action bank.

We are also asking people to write to their local MP to share Good Lives with them. We have put together a template and an information pack to support people to do this. The letter asks MPs to write to the Minister for Disabled People about Good Lives and to push for a commitment for the equity of people with learning disabilities in their next manifesto. Follow the QR code for more information.

Finally, we have a new 'Action for Good Lives' logo. We would love to see people using it on social media and in their work to show your support of Good Lives and its growing movement.

If you would like to get more involved or share what you are doing email [info@ldengland.org.uk](mailto:info@ldengland.org.uk)





Learning Disability England

### Some of the things we did in 2022

#### Learn and work together to solve problems

- 14 webinars and members sessions
- 18 'self-advocacy and family sessions'
- 1451 tickets used over 6 sessions at our annual conference
- 25 blogs and vlogs
- 59 events where Good Lives was shared
- Hosted Equal Treatment training 12 self-advocacy and 12 family groups on anti-racism



#### Influence policy and help members be heard

- 8 policy, joint committee or consultation responses, including Down Syndrome Bill and Review of Human Rights Act
- Worked with members as part of Social Care Futures
- Supported 10 research projects, including Coronavirus and People with Learning Disabilities Research



#### Representing Members views

##### We've helped members contribute to

- Human Rights Act
- Building the Right Support
- Small Payments
- NHS Long Term Plan Refresh
- Covid Inquiry Terms of Reference and campaigning for accessible information
- Supported Living Coalition



#### Living our values

- 2 new staff recruited inclusively
- 6 new Rep Body members elected
- Supported self advocates and families to lead in media responses 7 times



#### Membership and wider networks

- 14,600 Twitter followers
- 6,150 Facebook followers
- We sent 62 Newsletters to over 1700 members
- 643 individual members
- 182 group or organisation members



#### Learn and support partners through projects and research

##### We developed and maintained our partnerships



FIND OUT MORE AT LEARNINGDISABILITYENGLAND.ORG.UK

## Lunch Time Drop-Ins

### The rights of carers and representatives to be seen and heard



Changes in the Health & Care Act 2022 saw an extension of the legal duty to involve carers in NHS decision making.

Chat with Ivan Olbrecht, one of our Member Representatives, about what this can look like.

## 'My Own Front Door'

This exhibition is part of the 'renting your own place' research project with York University and the UCL Home Team. The posters were created by people with learning disabilities who rent their own homes and show what it is like to be a renter.

As part of the exhibition, you will be able to create your own poster to tell us about where you live.





# Will you support us? My Vote My Voice



Dimensions, United Response, Ambitious About Autism and Mencap have teamed up to launch a campaign to encourage more people with learning disabilities and/or autism to vote in the next general election and My Vote My Voice needs you to join as a supporter.



There are 1.5 million people with learning disabilities in the UK and 700,000 autistic people. Imagine how much more attention policymakers would pay if half or even a quarter were to vote. We can't do this alone and need your help to spread the word.

We are asking you as fellow social care providers, charities, campaigners, individuals, networks, advocacy and self-advocacy groups to join us and help deliver the My Vote My Voice campaign using our free resources and toolkits.

We need more people with learning disabilities and/or autism to vote in elections, and are confident that collectively we can make change happen and ensure that everyone's voice is heard. Together, we can help more young people and adults to be interested in politics, understand the importance of voting, register to vote and, ultimately vote in the next general election.

In showing your support for the campaign you can make sure that these tools and information reach the right people, carers, support workers and organisations across the country.

The My Vote My Voice website has easy read guides on how to register to vote and how to support someone to do so. Plus, you'll find tips on how to make an event of voting day and commentary and updates on key political issues in the news. My Vote My Voice not only gives people with learning disabilities and autism the confidence to be involved in politics, but also those supporting and caring for them.

Show your support today by visiting:





MacIntyre

Providing support...your way

# From Strength to Strength

Sui-Ling has worked for MacIntyre for a number of years and is a Lifetime Member of Learning Disability England.

Having a job has always been important to Sui-Ling as has people having their voices heard. Sui-Ling has brought these two things together in her past roles in presenting Channel 4 News and Radio 4 documentaries. It seemed natural that Sui-Ling should have her own chat show to be able to use these skills and to use it as a way for people to share what is important to them.

Sui-Ling has gone on to present her show live at a number of MacIntyre events and has been able to use this as a vehicle for change where people can share their experiences and what they are passionate about, raise awareness about what they have been working on and inspire others. Sui-Ling reflected that, *"It was really good talking to lots of people."*



When asked about how she feels about her work more generally Sui-Ling says, *"I am quite busy. I enjoy doing what I do; I have done quite a lot. It's good the things I do with the team and it's good to be paid"*. This year looks set to be another busy year for Sui-Ling.

Watch the Sui-Ling Show here:

As a result of lockdowns the show began online where she has interviewed a wide variety of people, finding out what is important to them in their lives and job roles. Reflecting on her work in 2022, Sui-Ling said, *"I feel proud of what I have done this year. I've talked to lots of interesting people on Zoom."*







# Its in the bag!

Choice Support is a national charity, formed in 1984, supporting autistic people, and people with learning disabilities or mental health needs.

Our values haven't changed over the years. We are ambitious, continuing to take bold steps forward to promote the rights of people we support. We value people for who they are, and we expect everyone we support to be respected in society.

Our recent work includes the VIP Red Bag scheme which was developed to tackle health inequalities faced by people with learning disabilities. Many people with a learning disability die over 20 years younger than the general population and often from preventable causes. The scheme began in Wakefield in 2022 aiming to highlight to hospital staff that the person with the Red Bag requires additional support and may need reasonable adjustments during their appointment or stay in hospital.

Funding was secured through several sources, including Mencap Treat Me Well campaign, Morrisons Community Fund and Wakefield CCG/NHS England. This funding has enabled everyone in Wakefield on the learning disability register to have a free bag.

The project has been moving from strength-to-strength, with over 1200 bags given out. This has been

achieved through support from the local Complex Needs team, care co-ordinators, other service providers and through various events.



There have been positive changes for people who have used the VIP Red Bags. Hospital staff have known where to access people's hospital passport, followed best interest routes and made reasonable adjustments to make sure people have got the right care and support for them.

We would like to roll out Red Bags nationwide. This would share the benefits of the scheme and the work we have been doing on annual health checks and hospital passports to allow for more continuity of care across neighbouring hospitals.

Find out more here:





# Choosing Where and How You Live



Look Ahead, has been a not-for-profit care and support provider for 50 years.

We believe leaving home as a young person should be exciting. Deciding where you live, and who you live with, is usually a positive step into independence, but this is not always the case for young person with a learning disability. While some people end up stuck in hospitals and secure settings, others do not get to leave the family home after school or college either.

This is a challenge that Good Lives can help us find solutions for.

At Look Ahead, community-based supported housing is key. It ensures young people with learning disabilities can make informed choices over who they live with, where and how they can live fulfilling lives within their communities.

We're committed to ensuring young people's voices are heard, and their best interests prioritised. We know how important the views of family, health and social care professionals, teachers, and others within the young person's support circle can be in making that happen.

Working in partnership means people



can live how they choose, connected to the community and relationships that are meaningful to them. It also makes the changes as smooth as possible for everyone.

We've recently opened a new service in Kent that does just this. The service supports five young people with complex needs in transition from home, residential schooling, or long-term hospital placements.

Our service offers people a homely space of their own, to decorate and furnish as they wish. Everyone has a one-bedroomed flat and is supported to build the life they want in their local community.

Planning for transition and making sure we get it right from the start is a really important way that we can help people live good lives.

Find out more about our work:





# Working Together for Quality of Life

## SEEABILITY

Live. Love. Thrive. Belong.

Good Lives brings together people's ideas about what it will take for everyone with learning disabilities to be able to live a good life. It was co-produced based on what's important to people with learning disabilities and in partnership with families and organisations.

At SeeAbility we've used the principles of Good Lives to develop a programme with similar aims, which we've called our Quality of Life strategy.

The core aims of our charity are to support people to live, love, thrive and belong. However, measuring how well we deliver these aims can be a challenge.

The Quality of Life strategy seeks to make these ideas more real, and help us understand whether we are getting things right for everyone we support.

The strategy has been developed jointly with the people we support and those close to them. We know lots of things come together to make up a person's life - which we have grouped into eight areas called life-domains.

The life-domains include key areas such as relationships, communities, and



health. For someone like James, who we support, the life-domains can be used as a practical tool. They help James think about what changes he wants in his life, and they kick-start actions that will support him to achieve his goals.

By listening to James and scoring his satisfaction in each life-domain we can measure his progress as the strategy rolls out. At organisational level looking at everyone's scores will also help us understand how we are helping people as a provider of support and it will tell us what we can do differently.

We believe the Quality of Life strategy represents working together at its best. Most importantly though, we are confident it will support James and many other people to live their best lives.

Watch our short film on what quality of life means to us:





# Using the Law to achieve Good Lives

If you were to write a list of actions that will improve lives, “instructing a lawyer” might not make your list. I think it should.

Two cases in 2022 help explain why:

- Suffolk County Council stopped funding family holidays for two disabled brothers as they didn’t consider the cost of the holidays and entrance fees for recreational activities were care and support needs. The brothers were provided with year round support by their mother. Having a holiday meant that she had a bit of a break. They made a legal challenge. The Court said that the Council should still fund their holidays as they were part of the eligible care needs which the Council had to fund. The outcome of the case means that Councils now understand that “eligible needs” under the Care Act includes access to recreational activities and holidays.

- The London Borough of Croydon had only agreed to fund 35 hours of support for a person with learning difficulties despite an assessment that they needed 24 hours of support. A judicial review by the family of the person supported led the High Court to decide the Council had acted unlawfully. The case will help to get the individual concerned get the support she needs.

Anthony Collins Solicitors exist to use the law to improve lives, communities and society. Examples of how we do that include supporting,

- at Inquests so learning is identified to prevent future deaths;
- individuals who have suffered brain injuries. Helping them secure sufficient compensation to meet their needs;
- by acting as deputies for people who lack capacity, ensuring their best interests are met;
- providers to develop and register new services for people with learning disabilities;
- to make sure they are properly funded for the work they carry out; and to agree appropriate terms with landlords to ensure high quality housing provision for the people they support.

If you would like a conversation about how we can support you, your family or your organisation to achieve good lives in 2023 please get in touch with

[matthew.wort@anthonycollins.com](mailto:matthew.wort@anthonycollins.com)

Or visit our website



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