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Achieve together



Official Conference Newspaper

2024

Policy and Politics for Good Lives

Welcome to Learning Disability England's 2024 conferences



Between the upcoming election and the action we all know needs to happen to ensure people with learning disabilities live Good Lives, 2024 is set to be a busy year.

We hope this year's conferences can help everyone start the year off right – connecting with allies and finding opportunities to stand in solidarity together.

The conference is focused on Policy and Politics for Good Lives. We've got a brilliant collection of speakers, workshops and drop-ins lined up—even if we do say so ourselves!

Check out this paper to hear from this years conference sponsors, who have each shared an article about work they are doing towards Good Lives. You'll also hear from the Representative Body about the work they've been doing in the last year and how they work together to represent members.

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Stronger, Louder, Together!



Removing the Cloak of Invisibility

A sense of belonging, being included and valued is critical for us all. In the field of positive psychology, Dr Seligman sets out a theory of the building blocks of wellbeing – the PERMA Model.



This model describes five elements that are important for us all to lead happy and fulfilling lives. The PERMA model focuses on Positive Emotion, Engagement, Relationships, Meaning and Achievement.

For people with severe or profound learning disabilities being seen, heard and included is more challenging. In order to enhance relationships, to have meaning and to achieve in life those people need to be visible, to be present and valued when it comes to policy and other key decision making.

The mantra, ‘Nothing about us, without us’ is important here. People with severe or profound learning disabilities are often invisible, and therefore forgotten when it comes to policies at local, regional, and national levels.

Collectively, we can work together to

change that, to ensure people with profound learning disabilities are present, visible and have a voice. Indeed the ‘Supporting people with profound and multiple learning disabilities, Core & Essential Service Standards’ urge leaders in organisations to ‘Demonstrate inclusivity of people with profound and multiple learning disabilities in all their practices and provisions’. We all therefore need to think about how we achieve that. If we all do that much better, people with severe or profound learning disabilities will be more visible and have good lives as a result.

Campaign 4 Change advocacy group, which includes people with profound and multiple learning disabilities in its membership, recently presented on the topic of ‘Removing the Cloak of Invisibility’ alongside PMLD Link at the Kent, Surrey & Sussex learning disability Community of Practice Conference. Let us all keep ensuring we support those people to be present, visible, and considered.



Watch the film using this QR code or in the film room today!





Pigeon Poo, Markets, Honey and Inclusion

Since we moved to our new base in 2013 New Prospects have been trying to be an organisation that builds community rather than fights for inclusion. We have written about this on Citizen Network Research.



In essence we try to be nosy and helpful and get stuck into lots of things that shouldn't really be any of our business...here's one example.

We've been nosy and helpful at Whitley Bay Metro station for years and just before Covid we almost accidentally found ourselves running a Community Market on the last Sunday of every month.

The market showcases local produce, crafts, music, and environmental issues. It is not badged as a disability event, but as a platform for everyone to contribute as equal citizens. Small profits from the Market support the Community Wildlife Garden next to the station.

The market is run by volunteers, including people supported by New

Prospects and staff who volunteer as equals.

The market provides a place for John to sell our 'Whitley Bee' honey - an enterprise we hope will, in time employ people. It gives Caroline (a recent escapee from hospital) the opportunity to lead Proggy Mat demonstrations and gives Simon the chance to collect fees from stallholders, the job everyone else hates, he is a born debt collector!

People organising, contributing and sharing gifts skills and talents as equal citizens.

Community building isn't always warm and fluffy – Market days start at 7am sweeping up pigeon poo and swilling urine from the corners and collecting other evidence of the anti-social behaviour the station is known for.

We have plans to expand the market and create a bakery, food hub, and enterprise space in some disused buildings. We want to offer more opportunities for work, volunteering, and contribution for everyone. We do still like fighting for inclusion too!





‘A rare and precious thing’ and ‘wonderfully chaotic’ **– Hearing from Learning Disability England’s Representative Body**

Angela Catley and Tim Keilty are on the Representative Body of Learning Disability England and give their take on what’s involved.

The purpose of the Representative Body is to make sure that all three ‘voices’ involved, Self-Advocates, Family/Friends, and Paid Supporters are united in the fight for Good Lives for people with learning disabilities. Rep body members are elected to bring the views of their allies to the table.



Tim Keilty

The Representative Body of Learning Disability England is a wonderfully chaotic thing to be involved in.

I sometimes think that if you were designing an organisation which was quick and efficient you definitely wouldn’t do it like Learning Disability England!

I have always found the Rep Body to be a really inclusive way of working. Painstakingly inclusive, if I’m honest - sometimes excruciatingly inclusive.

I can truly say that anything of any great importance that comes out of Learning Disability England has spent a lot of time in Learning Disability England being debated, mulled over and agreed upon. Agreed upon slowly, carefully, ensuring every voice has been heard – with the focus of Good Lives beyond the room (or the screen) always at the heart.

I sometimes feel guilty that I don’t respond to emails or join in as many debates as I should, but I’m confident enough in my colleagues that whoever is involved follows the same inclusive approach, trusting each other and a

practical demonstration that we are Stronger, Louder, Together!

Angela Catley

I am new to the Rep Body and have to say Tim is right...painstakingly inclusive it is.



But it’s also a joyous, sometimes messy, space for different people, with very different perspectives, to discuss, debate and agree. We link with Learning Disability England members to hear what they think, then represent those views as best we can.

Over the last year I have been involved in discussions about topics as diverse as the regulation of care services, how to get MPs to engage with the Good Lives Framework, the Leaders List and the Down Syndrome Act.

We have proper meetings, online meetings, quick chats, email debates, sometimes planned but often not. We always take things seriously but never forget to have a laugh. Good lives for people with a learning disability are always front and centre.

It’s never boring, always infuriating and somehow...just right!

We have started hosting **‘Meet the Reps’** Meetings twice a year. Join your reps to share what's important to you.



SCAN ME

The next meetings are:
Self-advocates: 17th April
Families: 16th April
Paid Supporters: 18th April
Book using the QR Code



We asked our fellow Representative Body members to tell us why they think the Rep Body is so **important** and they said:

A fly on the wall would be astonished by the depth of discussion and agonising that goes into everything we do. We listen, learn and make sure that issues are considered from many perspectives. **Liz**



I think the rep body is important as it works to bring the views of all members together for discussion and action. Having people, families and providers of services all focussed on what works best for people with learning disabilities is, to me, a rare and precious thing. **Kate**



Learning Disability England uniquely brings people together like my brother, mother, myself and the people who support Tony in unity for a common cause. **James**



We asked our fellow Representative Body members to tell us how they think the Rep Body **helps people to live Good Lives** and they said:

How it helps good lives by listening to everyone's stories about working with people of all disabilities as not all the same. That is a useful tool as a guide to know what has been done well and what needs to be improved. and what new skills and experience we have all gained. **Kumudu**



It brings everyone together, and that is why we have the good lives plan which supports organisations, self advocates and families to make sure that the good lives work happens and it is the members plan not LDE's plan. **Scott**



Members of the Rep Body get everywhere! Every week, a member is meeting with organisations, members of the government, health and social care bodies all with the intention of increasing awareness of the rights of people with learning disabilities. **Marianne**



I volunteer to represent Learning Disability England members especially on matters relating to people's safety, wellbeing and health - to help people live good lives. I have spoken in meetings with the Care Quality Commission, the Nursing and Midwifery Council and with government. **Ivan**



LDE and the rep body work collaboratively with other partners to help people live good lives. We work to bring lots of voices and people together. Like with the covid vaccine, it was important that people came together and said we need to prioritise people with learning disabilities. **Jack**





'Jasper Pickles' - exploring health inequalities

MacIntyre

Providing support...your way

In 2023, some people from MacIntyre attended the More than a Provider event where they met Made by Mortals. Made by Mortals work with people who have lived experience to create characters and stories that people then listen to, to be able to understand other people's experiences - to walk in their shoes.



"I felt really scared at first, but I enjoyed going into the same sound studio where pop stars had recorded music" - Jess

"It was brilliant fun! We all had to choose which lines to say." - William

"When we first started with Made by Mortals I enjoyed doing the Zoom discussions, what the plan was going to be like and what the group was going to be doing. I also liked the drama things that we did and had fun. It was really good. I loved the studio, it was amazing." - Sui-Ling

Everyone was so impressed we decided to work together to make our own called "Jasper Pickles Climbs Everest". The story raises awareness of the health inequalities faced by people like Jasper, and helps people think about what needs to be done in the future to stop this happening and make things better and equal.

The group met on Zoom to create the character Jasper and his story, based on their own life experiences.

"We all had to figure out the story and character together" - Vicky

The music was then created by a group of people in Warrington. It was then off to a recording studio in Manchester to record it.



Listen to "Jasper Pickles Climbs Everest" using this QR code

SCAN ME





Voices United gets our vote

A Choice Support group passionate about encouraging more autistic people and people with learning disabilities to vote, is launching a newsletter called *Voices United*.

The Our Rights Group is a self-advocacy group that brings people together to discuss the issues that matter to them. The group aims to raise awareness of different campaigns, to make members more aware of their rights, and improve how they are supported.

There are currently three leading members of the Our Rights Group: Shalim Ali, Shiu-Ming Man and Andrew Sperinck.

They are hoping that Voices United, will help more autistic people and people with learning disabilities engage in politics.



With a general election happening in 2024, Voices United couldn't have come at a better time.

Shalim Ali is an experienced campaigner who has been involved with the Our Rights Group for many years. He says: *"We are working hard to make sure people with learning*

disabilities and autistic people know all about how to vote."

Choice Support is a partner in the My Vote My Voice Campaign, led by Dimensions, United Response, Mencap and Ambitious About Autism.



Shalim continues by explaining that the My Vote My Voice campaign is about making people understand how the voting system works, so it is important that there is easy read information available.

Andrew added: *"We are putting together Voices United to deliver to all the services that we provide."*

The group are hoping Voices United will help recruit more members for the Our Rights Group and help increase their budget, so they can support more important campaigns like My Vote My Voice.

As well as championing the My Vote My Voice campaign, Shiu-Ming Man says Voices United will feature interviews with senior staff, Trustees, and run competitions. It will be an important part of how Choice Support keeps everyone up to date with what's happening.



Learning Disability England

Some of the things we did in 2023

Learn and work together to solve problems

- 24 **webinars and members sessions**
- 10 **'Members Network Meetings'**
- Held a 3 part **annual conference** with events in London and York and online
 - Bringing nearly 200 members **together in person**
 - With 702 tickets used **online**
- 25 **blogs and vlogs**
- Presented at 30 events, sharing **Good Lives**



Film Room

During today's tea and coffee breaks and lunch we will be running a film room to showcase members work and campaigns.

We have films on all areas of Good Lives, including: Leadership training, coproduction, staying healthy, and the history of self-advocacy.

Thanks to all the members who have shared their videos!



Influence policy and help members be heard

- Met the **Minister for Disabled People**
- 5 **policy, joint committee or consultation responses**, including Down Syndrome Act Call for Evidence
- Worked with members as part of **Social Care Futures**
- Supported 9 **research projects**, including 'No Research About Us Without Us'
- Coproduced and launched a **Housing Guide**



Representing Members views

We've helped members contribute to

- Ticket Office Closures Campaign and consultation
- Right to Visiting in services campaigns and consultation
- Down Syndrome Act call for evidence
- Building the Right Support action plan CTR policy
- Special School Eye Care Service
- Small Payments and Mental Capacity
- Oliver McGowan Mandatory Training Code of Practice
- Accessible Information Standard



Good Lives Action Bank

Throughout 2023 members shared actions, evidence and work that contributed to making Good Lives happen in the Action Collection.

We want to keep sharing and creating opportunities to learn from each other. If you would like to share something as part of the Action Bank please send it to:

info@LDEngland.org.uk

Membership and wider networks

- 15,199 **X (Twitter)** followers
- 6,600 **Facebook** followers
- We sent 48 **Newsletters** to over 1900 members
- Over 500 **individual members**
- Over 150 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





A Good Life Is a Creative, Connected Life



Sometimes you witness something that perfectly captures how amazing the future for social care could be. Such a moment occurred with Donna and her blanket at one of our Connect & Do sessions recently.

Connect & Do is Certitude’s peer-led community arts and wellbeing programme. It’s free and open to everyone living in London, delivering around 50 workshops a month to over 200 participants.

Living a creative, connected life

Connect & Do came about because people we support wanted to be active players in their communities. People wanted to develop and build social connections based on their interests, not their diagnoses.

We knew cultural, structural and societal change was hard and takes time, but we also knew we had thousands of experts by experience with an loads of sharable skills, and that together we could push for the changes we all need.

How Connect & Do began

We began with grassroots projects with peer facilitators and let them grow organically. We made sessions available to everyone, regardless of whether or not they drew on social care.

The dynamic between ‘staff members’ and ‘participants’ shifted as the sessions felt less like services. Genuine friendships were formed between people who traditionally receive support and members of the

wider community, whose paths may never have crossed.

No looking back



The Connect & Do programme has grown to include art, craft, sewing, creative writing, music, drama, relaxation and gallery workshops. We’ve also published books of peer facilitators’ worksheets and partnered with several arts organisations.

But back to Donna and her blanket.

Donna lives alone and is a regular at Connect & Do workshops. Her mother died recently and she had shared how difficult it’s been for her.

Donna arrived at a sewing and craft workshop that day carrying a large wool blanket that her mother had been working on at the time of her death. With the support of a peer facilitator, Donna sat down and shared stories about her family.

As she talked, she finished her mother’s blanket. It was a simple moment, but one that spoke of healing, friendship – and the power of creativity and connection.



Listen Up!

By the Listen Up team at SeeAbility



Live. Love. Thrive. Belong.



We need to make sure that social care is on the agenda in each party's manifesto, as this is key to ensuring people get the right support to live the lives they want to live.

We'll be working in collaboration with other organisations to ensure we reach our goals:

- Social care for working age people to feature more strongly in the media and reform debates.
- Learning disability to feature in party manifestos and agendas in run up to the general election – working with Learning Disability England and My Vote My Voice to ensure that this is an accessible general election, where manifestos are in easy read.

We're SeeAbility's Listen Up team and we all have lived experience of disability. We work to raise the voices of people with learning disabilities, autism, and sight loss to ensure everyone has equal choices and opportunities to live, love, thrive and belong.

We do this by influencing attitudes, raising awareness, and changing policy where needed. Our work will shape a future where disabled people can participate as equal citizens.

We work in partnership and lend our voice to important campaigns. Coproduction means the balance of power is shifted towards inclusion for all.

We don't want someone else to speak for us. We want our own voices to be heard.

In the Listen Up team, we all know that this next year is a big one for influencing and leading change. There will be a general election and so it's the perfect opportunity to reach out to have our voices heard.



- The health inequality agenda at NHS England moves forward for people with learning disabilities and autism.

If you would like to collaborate with our team on any of our goals, please get in touch with Scott Watkin, Head of Engagement. His email address is:

s.watkin@seeability.org



How can I get involved in Good Lives in 2024?



We have lots planned for 2024 to help make Good Lives happen. We hope you will get involved and join us in taking action together!

Good Lives Manifesto

Over the autumn of 2023 a small group of members started working on developing a Good Lives Manifesto. In January we shared a first draft of shared messages with members. There will be a session today where you can tell us what you think.

New Chapters

When we first launched Good Lives the framework had 6 chapters – we chose them based on the priorities of people with learning disabilities. Members have shared what they think should be next.

Health chapter



In November 2023 we started to work with Bild to write a health chapter. Health is a significant priority for members. In January we held our first meetings to

understand what everyone thought were the barriers and actions we needed to take to help people live healthier lives and access good healthcare. You can still take part in the survey to share what you think.

Transport Chapter

Members have shared the importance of good transport as an enabler of Good Lives. When transport isn't right, it stops the other parts of your life working. We will start working on a transport chapter in March. You can join our Members Network Meeting to be part of the start of that conversation, scan the QR code for details:



SCAN ME



People with learning disabilities from minority ethnic communities



There is growing evidence about the racism and serious health inequalities faced by people with a learning disability from minority ethnic

communities. We aren't sure Good Lives has done a good enough job at representing those experiences yet.

In 2024 we want to think about creating a new chapter or developing the current ones to ensure the voices of people from minority ethnic groups are well represented. If you would like to be part of work around this we would love to hear from you, email:

Rachael.hall@LDEngland.org.uk



Using the Law to achieve Good Lives

Anthony Collins is proud of its purpose to improve lives, communities and society.



It is a real privilege to advocate for the health and social care sector, the people who receive support and the dedicated colleagues who deliver care.

Sadly, the current law for mental health, the Mental Health Act 1983, is very old and makes the lives of those experiencing a mental health crisis much harder.

A new Mental Health Act was proposed by the Government, but the release of the new laws have been postponed.

There was no mention of the new Mental Health Act in the King's Speech in November 2023.

The King's Speech is an opportunity for the Government to share its priorities for new legislation.

The new Mental Health Act would have outlawed the inappropriate detention of

people with a learning disability and autism, and introduce a new right to let people who have been ill set out how they want to be cared for when they fall into crisis.

Recent news and reports of poor experiences in inpatient units for people with learning disabilities and autistic people means that many care industry organisations are lobbying the Government to put mental health law reform at the top of the agenda.

Greater funding to community mental health services is desperately needed.

The Government's failure to properly fund mental health services plus its failure to update the law in this area ignores the real challenges people face within the healthcare system.

The system should support their access to care.

At Anthony Collins, we have a specialist and experienced team of health and social care lawyers who are passionate about the important work of their clients in and how we can encourage policy changes to improve the lives of the people at the heart of health and social care services.

Anthony
Collins



Empowering people we support to have a voice

Future Directions is a not-for-profit, values-led social care provider for adults with learning disabilities and complex needs. We deliver services across Greater Manchester, Lancashire and Yorkshire, including outreach, supported living and residential services.

One of our values is to 'Put People First'. We believe it is important to actively involve people we support to ensure we are continuously improving our services and supporting people to have fantastic lives. We offer a range of opportunities to ensure that the voices of the people we support are listened to, heard and acted upon.

One of the ways that we do this is through SPICE (Supporting People into Community Employment), a group of people with learning disabilities and autistic people, who are employed by Future Directions as 'Experts by Experience'.



SPICE get involved in lots of projects, including quality checking our services, and delivering training for all new employees on our staff induction. Our 'Confirm and Challenge' group meets



regularly to find out what we are doing well and what could be improved. These meetings are co-chaired by a person we support, and one of our non-executive directors who ensures effective communication to and from our Board of Directors.

SPICE also work with external organisations and within local communities to share knowledge, breakdown barriers, increase awareness and understanding, and improve lives.

Employing people with learning disabilities and autistic people helps to challenge stereotypes and foster positive attitudes. This has helped to shift the power balance within Future Directions and ensure that people we support have a meaningful voice, and are at the heart of everything we do.

By involving and listening to the voices of autistic people and people with learning disabilities, we are able to live out our values and ensure people we support are happy and have great lives.