

Good Lives 2020

Notes of our Meeting on 19th February 2020 in Birmingham



Who was there?

Sonia Antoniazzi
Eliana Riccardi
Catherine Farrell
Sui-Ling Tang
Julie Burns
Sarah Offley
Phil Moran
Neil Davies
Andrea Clark
Sarah Pickard
Danielle Garrett
Patricia Charlesworth
Jenny Carter
Lynn Jackson
Lorraine Mason
Tina Hughes
Gary Bourlet
Samantha Clark
Lisa Watchorn
Rachael Hall
Jordan Smith
Elmi Terjavjainena
Mary Woodall
Andrew Lee
Sarah (Andrew Lee's supporter)
Alison Owen
Caroline Jones
Matty Plant
Vicky Buckingham
Diana Morgan
Michael Ratcliffe
Paul Scarrott
Ben McCay



The important things we want action on:

Everyone had 3 dots to choose the 3 things they thought were most important to start this work with. These are the results:



Accessibility (added by the group)

9 dots



Arts and leisure

0 dots



Education (added by the group)

7 dots



Love and relationships

4 dots



Being safe

3 dots



Benefits and money

2 dots



A home

4 dots



Being an equal citizen

1 dot



Paid jobs

6 dots



The right support

14 dots



Good health

14 dots



Advocacy and self-advocacy

15 dots



Next we talked about what we know is already happening.

This will help us to understand how we can join work up.

It will help us learn about what people have already done.

It will stop us wasting time doing work that has already been done.



Accessibility

- Advocacy in Greenwich – easy read information
- Travel buddies – My Life My Choice franchising
- Brighton Buses are thinking of extending bus passes – so can be used over 24 hours a day
- Brighton – accessible easy read training for council
- Taking Part – can provide easy read literature
- Wider use of easy read – campaign (People First self-advocacy) – Andrew Lee
- C4C members Frankie and Samir campaign to have more changing place toilets in Brighton and Hove



Arts and leisure

- Great communities – Katherine Yates – Macintyre, Angela – Community Catalysts
- Arts/leisure, Our Way/Speak Up/DVC, lots of leisure activities
- Football team/Our Way
- Speak Up Rotherham – DVDs, Our Way – social events, DVC – night clubs, Speak Up – drama group
- Ace Anglia – film on Ace website, work with dance east and filmmakers composer and dancers to make films to showcase a different way to speak and also a bid to work with creative teams. To think about mental health and accessibility



Education

- Working with others in the partnership, educating the public re rights ie Ace Anglia – LD England campaigning - #Declareyourcare
- Advocacy in Greenwich – employment ambassadors – training staff about work
- Ace Anglia – teaching at University of Suffolk – SEND cause and social work cause
- Ace Anglia peer education – LDE health checks – working with LD England to link to 7 regions, online safety, rights law and discrimination



Love and relationships

- Supported Loving Network regional and local – Claire Bates – Supported Loving: advising and educating on relationships

- Choice Support – (Clare Bates) – Supported Loving, happily dating and relationships (Helena)
- Ace Anglia – part of the LD strategy for support and workstream.
- People/Suffolk People First - Planned conference in Dec 2020. Speaker Dr Claire Bates, Supported Loving, working with provider organisation to co-produce event



Being safe

- Advocacy in Greenwich – safe places – keeping people with a learning disability safe
- Taking Part – hate crime, West Mercia police, disability advisory group
- C4C members Stevie and David have made a short film about hate crime towards people with learning disabilities and autism
- Ace Anglia – safe places scheme, hate crime (co-produce) work by large group for police, community groups etc,
- Respond specialist (LD/ASD), SVA
- Suffolk People First “Being Safe” May 2020
- North and South hate crime forums – Our Way
- DVC/Speak Up/Learning Disability Partnership Board, Prioritise Me – Speak Up
- Safe: Our Way, Safe Places: DVC, Safe Places: Speak Up, AG West Mercia Police and DVC: Safeside
- Our Way and Speak Up – 3rd party reporting centre

- Travel training – DVC, Our Way, Speak Up
- Hate and mate crime – Speak Up, DVC, Our Way



Benefits and money

- Ace Anglia – Easy read versions of complicated information from DWP



A home

- Quality checking – (Supported Living) MLMC with Oxford Council
- Home – Our Way housing worker
- Speak Up/Our Way Quality checker
- Speak Up/DVC - care, treatment reviews
DVC/Our Way/Speak Up/Tenancy Management. Fire safety in the home – DVC
- Ace Anglia – Talk Tech 2 (great speakers) conference July 2020, focus on technology to live an ordinary life, co-produced conference – people providers, family



Being an equal citizen

- Being heard in government group (Brighton Speak Out)
- Self-advocates working on people with learning disabilities understanding/accessing democracy and voting
- Equal citizen – designed, democracy training with Outreach parliament – DVC
- Ace Anglia – regular visits to groups from parliamentary outreach, self-advocates,

filming local politicians, visits to Houses of Parliament



Paid jobs

- 'Walk it like you talk it' jobs campaign – MLMC
- Advocacy in Greenwich in paid job
- Brighton – paid outreach worker (Danielle!)
- Ace Anglia – Supported employment with Ace – paid short time for experience up to one year)



The right support

- Right support – personal budget support – Our Way
- Healthy Relationships training – DVC
- C4C member Fifi does a monthly pool competition in Coulsdon, Surrey, to raise awareness of Stay Up Late Campaign
- #CloseATUs campaign, People First self-advocacy – Andrew.director@peoplefirstLTD
- Respond – specialist therapies LD/ASD – forensic (people hurting others)
- Brighton Speakout and Healthwatch – doing focus group with CQC about people with learning disabilities being able to stand up to bullying in secure units
- Gig buddies/Stay Up Late
- C4C have a campaign called #Mindyourlanguage to tell staff and other professionals what kind of language is good

or bad when speaking to or about people with learning disabilities and autism

- Cuts impact action now (CIAN) People First Self-advocacy – Andrew Lee
- Respond – Specialist Therapies LD/ASD for children and adults – survivors of trauma, violence, abuse
- Speakout (Brighton) – ‘transitions’ project – advocacy and self-advocacy for people moving to being more independent. Planning with local authority – co-production on all 12 topics
- Ace Anglia – co-production always includes support workers, co-production of core skills framework in Suffolk, 25-areas/subjects



Good health

- Brighton Speakout – ‘Thumbs up for good health’ – Promoting annual health checks to Drs
- NHS England – mental health – work in ATUs to get people out of hospital
- C4C member Stephen leads a “walk and talk” group in Carshalton, Surrey, to help people be more physically active and make friends
- Ace Anglia – LD health checks, peer educator network, locally/regionally, possible national, easy read info, re-branded for 9 CCGs
- CTRs – MLMC, Sunderland PF, Bemix, Lewisham, Pathways
- Dementia Prospect, Sarah Ormaston, Macintyre

- Taking Part – health issues/social prescribing/NHSE England – ask/listen/do
- DVC/Our Way/Speak Up – Big health days, LD nurses



Advocacy and self-advocacy

- Self-advocacy – adult/woman/young people, MLMC
- Advocacy in Greenwich – self-advocacy
- Taking Part – experts by experience focus group
- Shout Out Group – Paul Layne – Macintyre/Catherine Farrell
- Self-advocacy Together – Bemix, Sunderland People First, Lewisham Speaking Up, MLMC, Pathways, People’s Parliaments – Lewisham, Essex, MLMC, Rotherham
- Self-advocacy Campaign 4 Change (C4C)
- Focus Groups – (EbyE) works with Partnership Board
- East Region – Co-production centre of excellence – Simon Stockton – NHS England
- Respond Action Group – (Experts by Experience)
- Advocacy/self-advocacy – all self-advocacy groups – DVC/Speak UP/Our Way
- Learning Disability Voices Network (LDVN!) – Brighton Speak Out, creating a network of self-advocates in the south east
- SEOEP - supporting each other equals power – People First Self-Advocacy – Andrew Lee

- More advocacy and support for people locally...campaign people first (self-advocacy) – Andrew Lee
- Better funding for local self-advocacy groups...campaign, People First Self-Advocacy – Andrew Lee
- Ace Anglia – Self-advocacy groups in Suffolk People First, network of self-advocacy groups, Norfolk Opening Doors and North Herts PF, regional meetings



What's missing?

People talked together about what was missing. This will help us to understand where the gaps are.

This is what people said:

- Some organisations and social workers still don't realise the importance of good support
- There is already law about a lot of things but organisations don't follow it. Andrew asked what it would look like if people actually followed the law. What would it take to make them? Like Article 19.
- Better pay for the well-trained staff
- Job coaches/employment support
- Education – inclusive to all
- Making information accessible to all
- Getting around – transport and understanding everyone is different
- Inclusion and fair treatment for all

- Starting my own family and being a parent
- Living in the community
- Travel buddies to go on holiday with
- Accessibility re changing places etc
- Taxi card scheme
- Good quality support
- Information we all understand
- Inclusive community
- Accessing equipment we need to live a decent life e.g. changing places, hoists in hotels etc, hiring of hoists difficult, accessible hotel rooms, profile beds, taxis and transport that fit larger wheelchairs, access to buildings
- To be able to get to places so we can meet friends and live a good community life even though e.g. use large wheelchairs, without planning months in advance and having to choose where to meet based on accessibility
- Issues about transport and bus/train passes not being valid in rush hour – how can people get to work? It's hard enough to travel when it's really busy.



We then all talked about how we think this work on Good Lives 2020 should happen.

We talked about what we thought the principles should be.

We talked about what to focus on.

This is what people thought:

- Advocacy in Greenwich/Lorraine: Friendship, lonely, disability training for benefit staff, activities in the evening and weekends, parent can stop people with a learning disability doing things like having relationships and living alone. They need more support and info about letting go and moving on. Easy read for voting, more choices for housing options
- Together All Are Able – Wirral, Respond – Tina/Jordan/Pat: Human Rights (Being Human), language, advocacy in homes and supported living, involve communities, education, quality of supported living, better transport system, teach more independence, better employment opportunities, paid self-advocates, promote safe sex and awareness
- Use LDE networks (connectors) to communicate
- Get a committee of volunteers to support plan in areas
- Be national hub
- An index to let everyone know what is going on in each area
- National planning for helpers etc, rooms, venues etc
- Support in putting together 'National Self Advocacy Group'
- Social media - Respond
- Use of rooms
- Connect with professionals
- Connect with people with a learning disability
- Promoting model

- Sharing evaluation of project



We talked about the 'must haves'.

These are like the rules everyone agreed for how we all will work together on Good Lives 2020.

People wrote these on green cards:

- Be my microphone – not my voice!
- When in meetings no jargon
- Use respectful words
- Be positive and offer solutions to get your point across
- If the approach doesn't work, think of a different approach!
- Be creative and original
- Working together, collaboration, co-production
- Equal values, respect
- Good communication and listening
- Experience is more important than qualifications
- Let me take risks
- Culture change by raising standards
- Keep to subject
- Trust – our ideas and work is not used without our permission – by LDE or others, or for other things

- Remember to be confident to challenge – use the law that is there
- Networking and telling people what we are doing and how they can join in, researching
- Joined up working imperative between ALL agencies
- Get right people around table in the first place
NHS/ASC MUST talk to each other
- Talk to each other – communicate
- All information accessible
- Easy read and accessible, different ways
- Must get permission before sharing info
- Keep it all accessible – writing, easy read and the meetings and buildings
- Good environment for ALL do different ways
- Learning disability issues led by people with learning disabilities
- Understand who has the money and who has the power to make sure they understand the situation on the ground
- Seeing real change
- National self-advocacy movement, bring people together, making accessible to ALL
- Celebrate achievements together
- You must include people with learning disabilities

- Inclusive – led by people with learning disabilities who are paid for the work they do and the knowledge they bring
- Must always involve people with LD
- Ask me what I think – I'm the expert by experience
- Listening to us and take seriously
- Really FULLY inclusive! For all (not tick boxes)



Then we talked about our 'nightmares'.

These are the things people thought must be completely avoided. People wrote these down on red cards.

These are the things everyone must agree not to do:

- Don't work alone! No labels! No jargon!
- Don't forget about the work we do
- Nagging, moaning and arguing to get your point across
- It's not a competition
- Don't just keep going things in the old ways that don't work
- Don't call us LD
- Don't call us service user
- Repeating the same failed approach
- Do not exclude people with PMLD
- Dismiss ideas, not be led (be individual)

- No controlling. Remember I'm human!
- Don't send out information unless it is in easy read and accessible
- Professionals and organisations should not go off doing things on their own
- Reviews/meetings taking place without the person present
- Not to speak for people with learning disabilities
- Don't speak on behalf of the person without talking with them first and having their permission to speak for them



What is Learning Disability England's role?

We then asked everyone what they thought the Learning Disability England team could do to help take this work forward.

Here are people's ideas:

- Create a catalogue of different groups/organisations/individuals online – something like this i.e. organisation/group/individual, what we do, where we do it, contacts
- Apply for funding for travel, accommodation, rooms and support
- Pull together people working on the same topics
- Helping work out who has the money and the control for each piece of work – then ensure it's inclusive

- Talk to universities – understand what research is happening, how it is funded and how it can link with people with LD
- Find out what BILD is up to. How can we link in?
- Put accessible resources on our website about how to apply for funding – basic guidance and links people with a LD can understand and use
- LDE need a key role to report progress so we keep up momentum. Linking up projects and communicating.
- Where there is a problem or blockage – come to LDE so we can communicate it with everyone and come together to find a solution.
- LDE look at membership – have we got a geographical gap? How can we fill it?
- Make sure members know who other members are in their area and also members who are working on or interested in the same issues.
- Help members to advocate for themselves and become confident spokespeople so it's always a person with a LD who speaks on every topic we are working on – connect with self-advocates who are willing to train and mentor other self-advocates.
- Joining smaller organisations together for funding bids so we have better chance against big organisations!
- Be the hub, bring people together, keep people informed, signposting to local groups
- Develop your awareness of what is where, local – LDE – local
- Share info about the work with local partners (other self-advocacy groups/commissioners etc)

- Share any work we do with others that we think will be useful (all of us)



Finally everyone talked about what they would do after today to help with this work.

We called these 'promises'.

Sam said these could be small things not just big things. They could be a promise to carry on the work people are already doing.

This is what people said:

- Talk to our local advocate groups about LDE
- Talk to advocate groups – Loraine
- Catherine & Sui-Ling (Macintyre) Share resources – names etc, marketing team - publicise work, share great communities work
- Taking Part – can share info with Focus SA group
- Tell Shropshire/T&W partnership boards what is happening
- Tell NHE National Advisory Group for people with learning disabilities/autistic people what is happening
- Link up with West Mercia Police/Independent Advisory Group
- Link into Bethpage – service providers, homes – supported living, days services, shared homes
- Campaign for Change – we will bring the priorities from today back to the group and see what new campaigns we can start around these topics.

- Advocating health, relationships, being safe, easy read local plan, the right support, benefits, housing. The Wirral plan – with the local council – covers all 12 topics
- Share the work of WMSAN to other groups outside the West Mids and invite along if they wish (DVC)
- Alison will share information with the group – Speak Up
- DVC will share the work that's happening via social media



Sam thanked everyone for their hard work.

People agreed it had been a good day and a good start to Good Lives 2020.