



## **Learning Disability Member Meetup – 19.05.2021**

### **On Zoom**

#### **Attendees:**

John Rozenstein - Chapeltown CAB  
Jessica Duffy - Time to Shine  
Ann Wilson - SLATE  
Helen McEwan - Hamara  
Melanie Maddison - Purple Patch Arts  
Carley Stubbs - Pyramid  
Lou Cunningham, Andy Rawnsley - Aspire CBS  
Paul Downes - Sense  
Sabiha Hussain - Hamara  
Aqila Choudhry - Love in Care  
Cath Lee - Leeds Mencap  
Sumaiya Ali - Hft  
Claire McNeill - Carers Leeds

Lisa Smith - LCH  
Claire Nixon - Advonet  
Madeleine Fahy - Connect in the North  
Megan Arundel - Leeds Cancer Awareness Project  
Dominique Burley - CHANGE  
Gwendolyn Wagner-Adair - Leeds City Council  
Tanya Bish - Carlshead Farms (Living Potential Care Farming)  
Mandy Haigh - Leep1  
John Preston - TCV Hollybush  
Jez Coram, Daisy Morgan, Kelly Bishop, Damian Dawtry - Forum Central

#### **1. Welcome / Intros**

Jez welcomed everyone to the meeting.

#### **2. Intro to new Autism and Learning Disability Coordinator - Carley Stubbs**

Carley is the new ALaDDIN Coordinator. The role emerged through the ALaDDIN digital inclusion network. Carley's role is to support this network

and more widely to coordinate further digital inclusion work in Leeds - to help raise the digital confidence of people with Learning Disabilities. Carley will work at organisational level too with 100% Digital Leeds. If you need to get in touch please email: [carley@pyramid.org.uk](mailto:carley@pyramid.org.uk)

### **3. Forum Central Learning Disability Communications - Break Out rooms**

We recently changed the format of the e-bulletin, which used to go out weekly and is now going out fortnightly. We are also developing a new website and have recently employed Kim Goulden as Communications Manager at Forum Central

We are sending out weekly specialism updates, so you should be receiving a weekly learning disability update email.

The aim of these first breakout rooms is to see if this weekly update is working for you, do you want it, are you reading it, is it lost in the bottomless pit of weekly emails, is it giving you the information you need? If not, what information do you want?

The attendees were split into 3 breakout rooms to discuss this and then each group provided short feedback.

#### **Break Out Room 1**

- All attendees confirmed they receive and read the weekly email and FC newsletter, usually scanning/skim reading rather than top to bottom, and share relevant parts with their colleagues
- Useful to promote their own work - works both ways
- All prefer email to other channels like social media - it's easier to keep on top of the information that way
- Activities, funding, national policy updates, changes in legislation and guidance were all mentioned as useful topics to receive information on, and Forum Central staff changes less relevant
- Website used only to look for meeting dates currently, which can be hard to find
- Everyone thought that a more up-to-date Learning Disability webpage that's easy to navigate and access would be useful.
- Important there's no duplication with Leeds Directory, Learning Disability health website for Leeds etc, and that the new website is developed so it's accessible for people with a learning disability

## **Break Out Room 2**

- Overall positive about current change to communications and seen as very helpful
- Very helpful to have a learning disability focused update on a weekly basis
- Potential to link Carley's Digital Inclusion updates into the weekly update so information comes from one source. Cross check contact lists.
- Andy and Neil at Aspire may be moving from a daily update to a weekly update. Potential to link Andy's updates into ours for one source of info. Cross check contact lists.
- Mixed on whether people open and read it, sometimes they do, sometimes don't, sometimes people come back to the email later on, or have it open to come back to.
- Useful as resource for organisations for signposting to other organisations
- Very useful and different sections used by different parts of the team, CEO uses strategic information, info more relevant to operations sent to them
- All agreed that email was best and twitter more of an echo chamber of information
- Felt that was currently included in the update was comprehensive and good balance with the guidance sent out with Andy's and Neil's daily update

## **Break Out Room 3**

- Bulletin emails are received and don't go to spam.
- People generally read these and find them helpful.
- The info included is not often relevant to private care providers i.e. info about funding streams.
- Might be good to hear about opportunities for private organisations.
- Would be really nice to profile or showcase a specific organisation in the bulletin briefly.
- Would be good if recruitment posts could be shared.
- Agreed email is the best format.

- Links to research projects have been really useful in the past as these could be shared within services and on social media to a wider audience too.
- Member updates could be in short video form and shared in network meetings like Damian is looking to do in Men's Health Unlocked.

#### Next Steps:

- Jez will review the notes from today, send them to the comms team at Volition and Forum Central, and adjust the weekly updates accordingly.

Please send information you want to share with the network through to Jez at: [jez.coram@forumcentral.org.uk](mailto:jez.coram@forumcentral.org.uk) and he will post it in the weekly update.

#### **4. Member Updates including Learning Disability Week**

**Learning Disability Week this year is 14th - 20th June** - Please send info of what you are doing ASAP to Madeleine and Luke at CITN so they can promote this: [madeleine@citn.org.uk](mailto:madeleine@citn.org.uk) [luke@citn.org.uk](mailto:luke@citn.org.uk) They can also include this in the newsletter at the beginning of June. In the week before Learning Disability week there will be a big chat on Zoom to explain what is going to happen - details on [their website](#) with all relevant events. 'Being Proud' is the Leeds theme. The awards from last year were put forward to this year and have had to be put back again unfortunately - they will take place when it all can be done in person. If your organisation is planning to put on an event during the week, Through The Maze has a form to fill out so they can add the event to the Through the Maze website and promote it on their social media. [please use this link](#)

**Pop-Up sessions** - These used to run at Technorth and provide a great opportunity for Forum Central members to talk to the Care Managers about your services, and what you can offer people with a learning disability in the city. Starting back up and planning to have 3 this year, first one will be online, which is booked up, second two after Summer, may be face to face – please contact Jez if you would like to book your organisation in.

**Resilience Survey** - Voluntary Action Leeds (VAL) have been working with Forum Central & other partners to launch a survey looking at the

Resilience of the TS in Leeds. It is important that as many organisations, both large & small take part in this survey. This same survey is being conducted across Yorkshire & the Humber. [Link to the survey here](#)

**Paul Downes - Sense** - Training workshops are available online in next few months - One around sensory walks and another on 'Connecting Differently Through Sport' - how to adapt activity and sport sessions for differing abilities. [Link here](#) for the Sensory Walks info and you can find the training here too.

**Megan Arundel - Leeds Cancer Awareness** - This organisation aims to raise awareness of the signs and symptoms of cancer and encourage screenings etc. Due to the pandemic all content is online for the moment - They are offering free online training and adults with learning disabilities are a main target area and they can offer adaptive sessions for them. Have had some really useful sessions recently with this group - Megan's email: [megan.arundel@uni.uk.net](mailto:megan.arundel@uni.uk.net)

**Andy Rawnsley - Aspire CBS - Contracting** - Contract extension to end of July this year - There is going to be a further extension of up to 2 years but this will move to spot contracting. They have continued to grant funds to 7 specific organisations for a few years - Had a meeting last week and they are intending to continue the grant funding arrangements in the same way as long as these orgs do a bit of a refresh towards in-person provision.

**Mandy Haigh - Leep1 - 21st June is Safeguarding Awareness Week** - Really want to find safeguarding stories around people with learning disabilities or any other safeguarding stories to feed back to the safeguarding board - Please contact Mandy and Dominique - [dominiqueb@changepeople.org](mailto:dominiqueb@changepeople.org)

## **5. Older People with Learning Disabilities - Sector Perspective including learning from Bee Together / Time to Shine - Break Out Rooms**

Leeds Older People's Forum and Time To Shine ran a project with Health for All looking at the issue of Social Isolation and Loneliness for older adults with learning disabilities. The project ended in September 2020.

Time to Shine are keen to make sure the learning from the project is not lost and there is longevity to the work that was done.

The Bee Together project was successful in that it:

- Produced inclusive, informal groups at cafes where people could make trusted friendships.
- Raised awareness through accessible information.
- Educated through training of professionals.

But the issues remain and findings reinforce a lot of what we already know, including:

- Issues of Loneliness and Friendship – e.g. people feeling lonely in the evening.
- People with mild learning disabilities may be living independently, not identifying as having a learning disability, falling through gaps of services.
- Inclusivity in non-learning disability groups.
- The impact of Covid restrictions on people's mental health, worsening anxiety, depression and crisis, limiting independence and choice.

We want to produce a scoping report with strategic recommendations to influence commissioners and the various Health Inequality boards in the city.

The aim of the session is to gather your insight from an organisational perspective delivering services in the city on what you think is needed, your examples of good practice, solutions and what has worked – this was one of the outcomes of the Bee Together project.

The attendees were split into 4 breakout groups to discuss this and then each group provided short feedback.

### **Break Out Room 1**

- Helen is working with an older lady with a Learning Disability who doesn't speak English as a first language and she needs ideas of how to support her - This lady obviously struggles on lots of different levels and Helen isn't sure of how to help her
- Claire said that older people do engage - However one issue is when older people are retired from their support services they don't

engage with things like People's Parliament as they don't see it as for them or they are out of contact.

- People in independent living who have mild Learning Disabilities and minimal support also sometimes see support as not for them, as they have never had a great level of support.
- There are still major issues in terms of digital inclusion, especially in older people as they don't know how or don't want to engage with digital technology.
- Drop in groups that people may have engaged with have either stopped running due to Covid-19 or their funding has stopped - Groups like Mencap's Out and About group and KeyRing. There is lots of change in general and sometimes it is hard to keep on top of where to refer people to.
- Engagement really depends on where people live sometimes - There is much more engagement from people in supported living. Also, sometimes whether someone attends a group depends on how safe and connected they feel in their community and in the community the group is held in.
- Things in general need to be more joined up in terms of the support offered - eg. Someone might get money to support themselves but then not know how to spend it safely or usefully.
- In general the group agreed that there must be a lot of older people with mild Learning Disabilities that they miss.
- Lou gave a good example that Aspire are striving to look at the full customer journey throughout their life - Taking ageing and the customers changing goals and priorities into account through this process.

## **Break Out Room 2**

- Megan (Cancer Awareness project) works only with groups referred to them so known to services - so she couldn't really comment. many of the people she works with tend to be over 50 just because of the age related nature of many cancers
- Tanya Living Potential - same, though they get people enquiring about being volunteers who they suspect have a Learning Disability. Not sure what happens after that or whether they send them off to get referred. They are able to keep people engaged for as long as they want generally - and then some can move to a dementia group - Over the Rainbow - where they can just watch/ pet things. (She recommends llama hugging)

- They would love to do outreach with the animals to older people and just to the public to try and find more people who would like to join - but can't afford to.
- Sabiha - Hamara - they have people up to the age of 55 in their Learning Disability general provisions, and they have a weekend group for older people. They meet people who have a mild Learning Disability and live in the community. There can be issues around carers and acknowledging someone might need support.
- TCV, have groups open to all ages & most people where they do have adults with mild Learning Disability who volunteer. They don't know if they have external support as there is no need to ask unless someone can't attend alone. They have an ASC provision which now has some very old members (they started as a cohort a long time ago and have got older). These people sometimes just vanish after age/or physical health related to age problems. TCV tries to accommodate people for as long as possible but also has to offer opportunities for younger members in the same group.

### **Break Out Room 3**

- Both Dominique and Clare work with people of all ages with learning disabilities
- It's been hard to reach these people during the pandemic and since services moved online - even with tablets provided, people don't necessarily have internet access, or they don't have a phone number for people. Especially difficult for people who don't have English as their first language. Younger people on the other hand have mobiles, hotspots etc
- Difficult to get older people to engage with digital even with a lot of training and encouragement
  - Carley attended a 100% Digital event about digital inclusion and people in care homes - lots of ways to build confidence in older people in using digital - would be good to link with Rachel Benn and others on this
  - Important to consider that digital has limits for older people e.g. factors like eyesight, hearing, people living with dementia, which people with a learning disability have a higher likelihood of developing
- Recruitment is hard especially with no face-to-face events, especially if people aren't already known to services



- Important to emphasise the value of local informal check ins such as people working in local cafes, taking notice of how people are

#### **Break Out Room 4**

- Overall a lot that was mentioned in the discussion highlighted the findings from the Bee Together report
- Leeds Mencap deal with children and younger people so harder for them to comment
- Leep 1 unsure of the numbers of older people that they support but have been dealing with many older people during the Covid period and have many successes with getting tech out to people and then these people participating in afternoon / evening sessions
- Digital Inclusion mentioned – some people have found it easier to transition to using tech, Leep1 had been working on digital inclusion before Covid so this helped. Some services have found it harder to transition to digital service.
- Very hard to determine the actual number of people falling through the gaps in services if not classed by ASC as having eligible support needs
- Very hard to find these people - how do you find the people who are isolated and lonely
- Covid period has set people back in terms of independence, choices and rights
- An individual with dementia was mentioned who withdrew further during this period
- Strain felt by carers and family carers when individuals not able to return to services
- Peer support group for carers was mentioned as in idea, question over whether this exists already – contact Carers Leeds
- A lot of people struggling in the community – older people with learning disabilities and dementia – one to one face to face support needed, funding with the individual
- Loneliness of people living in supported living, not having a choice about who they live with

#### **Next Steps:**

- Review the notes from today with Jessica
- Link the work into Being Social Task Group / Health Task Groups and the aims of the Being Me Strategy

- Time to Shine and Volition are organising an event in early July to share learning and the scoping report, would be good to partner with some organisations to host this event, if anyone is interested let us know now or get in touch with Jez and Jessica

## **6. Close**

Jez thanked everyone and closed the meeting.

## **Next Meeting Date**

Tuesday 27th July 2021 10:00 - 11:30pm

Zoom link:

<https://us02web.zoom.us/j/83115987856?pwd=bittNFdqRzV3NkVpYnVKbjBERlhXUT09>

Meeting ID: 831 1598 7856

Passcode: 906633