

Learning Disability and Autism Stakeholder webinar

Chat Transcript

15th April 2020

[3:00 PM] Lynn

Query from Mark Warren in Oldham I said I would raise -

How are people linking with primary care to link the phase 1, 2 and 3 shielded lists work that is happening to show we support people with a Learning Disability and join this up with the GP Learning Disability lists and wider support strategies. Some people will already be on shielded lists some won't given the latest national guidance to GP's does not include the Learning Disability as a cohort. GM are keen to explore thinking with colleagues nationally before they develop anything for GM as a whole. We believe something is due to be published on Friday (from SCIE) but not sure whether it covers this area.

This would help develop guidance on how we link with local community hubs, GP care plans, advocacy agencies and local LD teams.

This has come about as the number of people covid positive in supported housing in one area increases and there is a lack of joining up as described.

[3:01 PM] Jo Skinner

We'd really appreciate it if everyone could switch their cameras off and go on mute when not speaking to help with stability of teams thanks

[3:05 PM] Kirsten Lamb

I'm trying to raise the types of patient on a GP's learning disability QOF register for whom shielding should be considered. I am awaiting reply from RCGP. But GPs are allowed discretion so those at highest risk of respiratory problems should ask GPs about shielding

[3:05 PM] ray james

Welcome Dave, we have gone to Donna first and will come to you next for an update

[3:06 PM] sarah.coleman@mencap.org.uk

Hi all, re the FAQ on Gov.uk - please can we amend the wording to include social care professionals as people who can (ideally) recommend that an individual may need to go out for exercise more than others? At present, it just says medical professionals.

[3:06 PM] Jo Skinner

Hi Ray, Dave has just arrived

[3:07 PM] Kirsten Lamb

Can we have copies of slides after the meeting?

(1 liked)

[3:07 PM] Jo Skinner
Kirsten Lamb yes of course

[3:08 PM] Kirsten Lamb
The more information we can glean from data the better - especially around what constitutes higher Covid risk

[3:08 PM] vivien@thecbf.org.uk
We are publishing a resource for families whose relatives have to go into hospital and advising them to contact the LD nurses (where hospitals have them). Is there a national network- are they collecting data and issues and reporting them so they can be addressed? They would seem to be a good resource and source of intelligence.

[3:08 PM] lynn
Do we have data about the numbers of people leaving hospital well following a positive diagnosis and period of illness? Tameside General Hospital shared a story that was really positively received
(1 liked)

[3:08 PM] sarah.coleman@mencap.org.uk
Re the data, is there any intention/value in working with the team at Guys/St Thomas who are working with the COVID-19 symptom tracker I wonder?

[3:08 PM] Kirsten Lamb
Donna - thanks for really looking at data

[3:08 PM] Samantha Clark
Great to hear data is next on the list & there's a plan

[3:08 PM] sarah.coleman@mencap.org.uk
Agreed

[3:09 PM] Donna Glover
Lynn - can you share the Tameside information with me?

[3:10 PM] Samantha Clark
Large & small & Direct payment employers are still telling us PPE is not reaching them or a horror to source. Lots of stress & worry for people

[3:10 PM] Julie Newcombe
Any idea of rough timing on the social care plan?

Hyperlinks included – cannot copy into transcript. Will be included in FAQs and on the Futures platform

[3:15 PM] Kirsten Lamb
thanks Donna

[3:15 PM] vivien@thecbf.org.uk

new DNR related issue..... we have heard that a new phrase is appearing on records... "not for escalation" - i.e. no access to ICU. This was challenged successfully by a LD nurse...

[3:15 PM] Dave Nuttall

@Sam - re PPE for DP employers - will pick this up with colleagues after this call if you have any examples you can share?

[3:16 PM] Dave Nuttall

@Julie - social care plan imminent - I was expecting it today but haven't had an update on it today.... so will need to confirm.

[3:16 PM] Julie Newcombe

Thanks Dave

[3:16 PM] Samantha Clark

We've had providers members tell us stories of people leaving hospital with a DNAR on their discharge. The hospital responded positively when challenged but we are concerned about wider system response staying the same in that trust or team

[3:18 PM] vivien@thecbf.org.uk

yes, Sam- we need to ensure that everyone has access to someone who can support to challenge!

[3:19 PM] Julie Newcombe

Roger is that 24/7 visiting?

[3:19 PM] Dr Karen Dodd

Roger, please can we have a copy of the guidance re visiting so I can circulate it to the LD Senate (1 liked)

[3:19 PM] ray james

Query from Mark Warren in Oldahm I said I would raise -

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This has come about as the number of people covid positive in supported housing in one area increases and there is a lack of joining up as described.

[3:20 PM] vivien@theclub.org.uk

We have legal FAQ resource on our website that has lawyers answers to families questions about a range of things including DNARs and restrictions on visiting
(1 liked)

[3:20 PM] lynn

Visiting daily video update we produced this week Roger Banks -
<https://www.youtube.com/watch?v=fTYWH2aDuPY>
(1 liked)

[3:20 PM] Roger Banks

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0030_Visitor-Guidance_8-April-2020.pdf

[3:21 PM] Roger Banks

Thanks Lynn - will look at after this

[3:21 PM] Jo Skinner

Sarah Coleman we'll include that in the FAQs

[3:22 PM] Donna Glover

We're sending out a weekly learning disabilities focussed Coronavirus update bulletin from PHE - if you're not already getting it you can [sign up](#)

[3:22 PM] Dr Karen Dodd

Roger - thanks

[3:23 PM] Kirsten Lamb

I've commented to the SCIE guidance about shielding

[3:25 PM] Kirsten Lamb

One of the really difficult issues is that we don't really know who is at highest risk. However, given that 40% of LD deaths in LeDeR we need to consider high resp risk. I'm trying to focus on aspiration pneumonia risk, poor postural control, extreme scoliosis, PEG and NG feeding

[3:25 PM] sarah.coleman@mencap.org.uk

As you know we are seeing repeated examples of evidence that messaging is not getting through to all practitioners. What alternative routes are there to make sure the very top line messages about use of the CFS and DNACPRs get through? I have been wondering about using SCRs for example. Would it be appropriate for a safety alert? Any other ideas?

[3:26 PM] lynn

thanks ray james Dave Nuttall will share back with Mark and GM and suggest they connect for support to develop guidance

[3:27 PM] sarah.coleman@mencap.org.uk

Thanks Jo. @Donna Glover can we include a note in the FAQ on gov.uk too?

[3:27 PM] Donna Glover

Kirsten Lamb - agree very difficult. And shielding is a big ask that isolates people.

[3:27 PM] Roger Banks

With regard to people being discharged from hospital - there is guidance currently being drafted (is open on my laptop!) about the processes for discharge from Intensive Care Units and what the necessary step down facilities and processes may be. Will ensure that comments about ensuring people are informed about their conditions and prognosis

[3:28 PM] Kirsten Lamb

thanks Roger - can you share the link?

[3:29 PM] Kirsten Lamb

Herts is developing a proactive plan to try monitor those on risk of admission register to prevent behaviour escalation

(1 liked)

[3:30 PM] Ben Briggs

Roger Banks would it be possible to have sight of the draft guidance please?

[3:30 PM] vivien@thecbf.org.uk

What alternatives are being offered to medication?

[3:35 PM] Kath Bromfield

I spoke to our local police who weren't aware of the guidance on exercise. Can we encourage it being filtered down.

[3:35 PM] b.higgins@bild.org.uk

Building on Ashok's point (and Roger's response) we are hearing about increases in other restrictive practices as well as medication. The RRN is looking to develop guidance and a series of webinars on topics such as promoting minimal necessary restrictions in a time of increased restrictions (due to infection control). Ray/Roger - I will email you further info.

(2 liked)

[3:35 PM] vivien@thecbf.org.uk

we asked last week for the guidance to be proactively shared with police....

[3:36 PM] phillippa.ashcroft@voiceability.org

Claire - are you aware of areas that may not formally be bringing in the easements but by their decisions are inadvertently. We are seeing a lot of this where SW are making the decisions but it is not seemingly a whole LA decision to move to easements. What is LGA doing to cascade info? Thanks

[3:36 PM] ray james

My understanding is that the guidance has been shared with the police but again your help in ensuring it reaches everyone and is followed is appreciated

[3:37 PM] vivien@thecbf.org.uk

we are worried about inpatient services becoming more closed- especially as CQC inspections are reduced and external; people (e.g. families) are not allowed in. Big risk of more restrictive interventions....

[3:37 PM] lynn

Contact with families who have been had a letter from their care provider stating that 'if he needed to go into hospital, no support worker would be able to go with him.' The visitor guidance needs widely sharing

[3:39 PM] Julie Newcombe

Agreed Viv. Some very frightened families especially where there is Covid in the hospital.

[3:39 PM] vivien@thecbf.org.uk

i commented earlier about the potential role of LD liaison nurses here- they should be a resource we use better!

[3:39 PM] phillippa.ashcroft@voiceability.org

Really helpful Claire - thanks. Could we as a third sector help to get these to the grass roots too? Could you share your bulletins wider to the vol sector and other stakeholders? Thanks

[3:40 PM] b.higgins@bild.org.uk

As well as risk of increased restrictions in inpatient services there is also a risk of increased admissions due to increased stress and anxiety levels (and resulting challenging behaviour as Jim mentions)

[3:40 PM] Mrunal

Issues being raised by parent carers: 1. Different definitions of vulnerable; 2. Unconscious implementation of easements - even though some of them have not yet been invoked; 3. Need joined up co-ordination of priorities across health, social care and education services (e.g. understanding the risks given the tiny proportion of children in school - only 1.5%); 4 Coproduction (either individual or strategic) should not stop in this period

[3:42 PM] Claire Bruin

Phillippa thanks I'll double check that it's OK to send bulletins out through our networks - we'd probably use LGA colleagues in the Regions and ADASS regional networks to do this.

[3:42 PM] ray james

Thanks Mrunal, if anybody does want to share key updates here in chat please do.

[3:43 PM] Julie Newcombe

Is there anything that could be done to make it easier for those caring for loved ones at home who aren't on the shielded list? Eg getting shopping slots, meds delivered,

[3:43 PM] vivien@thecbf.org.uk

We should not be surprised that challenging behaviours are increasing when routines are so disrupted! we should be focusing on what we can do proactively to support people, to support staff and providers so that the persons distress is minimized rather than reaching for powerful medication

[3:43 PM] phillippa.ashcroft@voiceability.org

Ray, a mis-understanding amongst many LAs that independent advocacy is no longer available because of the Coronavirus Act. The duties to appoint advocates under the Care Act, Mental Capacity Act and Mental Health Act are not affected. Advocacy providers should be receiving referrals and have adapted our practices given the Covid-19 circumstances. Many thanks.

(1 liked)

[3:43 PM] Kath Bromfield

everyone may have post traumatic stress. People who have less control than we do, parent/carers and staff.

[3:44 PM] lynn

Trauma support

[3:45 PM] Dr Karen Dodd

The LD Senate included some guidance on Trauma in the guidance that we published <https://www.bild.org.uk/wp-content/uploads/2020/03/LD-Senate-Coronavirus-resources-for-use-by-families-27.3.2020.pdf>

[3:46 PM] Julie Newcombe

Support on the ground seems to be an issue.

[3:47 PM] lynn

I agree Viv staff working in keyworking roles will need trauma support too that can be planned for

[3:47 PM] Mrunal

The main thing is co-ordinated leadership across govt. / national agencies. E.g. understanding the cross system implications of easements

[3:47 PM] Samantha Clark

Mental health, well being & trauma - planning for the iimpact of this & recovery

(1 liked)

[3:47 PM] Donna Glover

@sam I'd like to see the models that are working

[3:47 PM] Salli Midgley

hi, we are currently developing plans with the restraint reduction network to better support providers in this time and avoid restrictions - key areas that are in discussion are

[3:47 PM] Roger Banks

I will pick up Ashok's point about alternatives to medication with colleagues in the team and the professional senate, Viv, Ben and others - see how we can focus resources and disseminate widely - and in primary care

[3:47 PM] Samantha Clark

Donna will e mail you as only got as a doc

[3:47 PM] Donna Glover

@sam fab thanks

[3:48 PM] Dr Karen Dodd

In our Trust we are developing some very short videos both for people with learning disabilities and for families/ staff. The first 2 are nearly ready - one on coronavirus and one on what is social distancing for people with learning disabilities

[3:48 PM] Donna Glover
@karen - keen to see these when ready, we'll share

[3:48 PM] Samantha Clark
We love Lynn's commitment to hosting the big party as well as all the videos

[3:48 PM] Lynn
Support on info - telling people they are positive particularly if they have lost someone to the virus

[3:49 PM] Dr Karen Dodd
@donna - will do

[3:49 PM] Kath Bromfield
any excuse for a party hehe

[3:49 PM] Jon Spiers
To add to Jim and Kath's points, the issue of PTSD/wider mental health issues post-lockdown for autistic people, those with learning disability and their families is likely to be acute. Research evidence from previous pandemics strongly indicates a high risk of post-event MH issues for everyone - and we're all aware of the pre-existing higher risk for our beneficiaries before this happened. This should be an urgent priority for both research and services planning as lockdown eases.

[3:50 PM] Donna Glover
@jon I will share that with my mental health colleagues in PHE, if that's okay?

[3:50 PM] Jon Spiers
Absolutely

We are beginning to plan with our IAPT colleagues some more groups for people with LD post the virus - we already run wellbeing groups jointly with IAPT - so this will be an extension to that work

[3:51 PM] Mrunal
I can bring my guitar to next week's meeting...
(2 liked)

[3:51 PM] b.higgins@bild.org.uk
Jon Spiers ray james- It would be helpful to have a discussion next week regarding planning for post lock-down

[3:51 PM] Lynn
Sam Clark - how big will NWR21 and the 3 National Self-Advocacy Conference be when it happens to celebrate all coming through this and all the missed birthdays

[3:51 PM] Jim Thomas
Post planning would be happy to join

[3:52 PM] Lynn
Thanks Ray

[3:52 PM] b.higgins@bild.org.uk
ray james thanks - very helpful

[3:57 PM] vivien@theCBF.org.uk
please can we have: LD nursing role- and feedback about on their the ground issues (as i mentioned a new phrase is emerging "not to escalation" on peoples records which has to be challenged), and also planning proactively for the issues we know will emerge (e.g MH issues, trauma support - getting people off the medication they have been put on to "manage" challenging behaviour.....etc)....
(1 liked)