

LOCKDOWN LESSONS FOR A BETTER SOCIAL CARE FUTURE:



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Pushing boundaries

Listening to the voices of people with learning disabilities and their supporters* during Covid-19.

Paradigm
May 3rd 2020



Frankly, people with learning disabilities and their families did not need the lock-down to understand what it means to be isolated and marginalised. But, as in many other areas of life, Covid-19 and the policy responses to the pandemic have magnified these experiences.

They have also illuminated on a small scale what will be required going forward if we are to build a more inclusive society that genuinely enables people with a learning disability/autism to lead a full life and participate as equal citizens. This needs to be the overarching purpose of new social care.

In what follows, we offer a small selection of these voices of experience.

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Concerns.

“Ever since the lockdown started, I’ve not had any real support. My support workers have been calling me once a week. I can’t Facebook on my own, I live with epilepsy, I can’t go to the Doctor on my own. I got told off for going to the pharmacy to get my tablets and they didn’t even send my tablets when I needed them. I have been told there aren’t enough staff to support me during this. This has made me really unhappy.” (Self-advocate, Wirral.)

“I can manage on my own but there are so many people who have mild or moderate learning disabilities who don’t meet the criteria for paid support. This is true even without coronavirus but really scary for people now who can’t go out. I know people are really lonely and scared.” (Self-advocate, London)

“I don’t have a phone that can do the things my friends are using – I can only make phone calls. Everyone is saying join this chat, join that chat...I can’t. I have to just have a phone with big buttons.” (Self-advocate, London)

“As a carer for someone with a complex learning disability I am stunned that no one has been in touch to check that she is OK. I can’t get to her as I am having to self-isolate. Sue thinks she is being punished. This is causing major distress. (Carer, London.)

“I really enjoy the video calls, but I keep running out of data and I can’t afford more.” (Self-advocate, London.)

“A friend of ours was very distressed at the weekend due to a neighbours dispute. The Police were called out and there was talk of a Section 136. It was all to do with lockdown and him not being able to follow his usual routine, to go on bus rides etc. It was very distressing and potentially it could have serious long lasting implications.” (Community worker, Skipton.)

“I haven’t been out at all for over 5 weeks. I live with my flat mate. Because of staff shortages there is only one member of staff most of the time. When we get our few hours of 1:1 support my flat mate goes out. My 1:1 support worker says she has been told by her boss that she is not allowed to go out with me. Why?” (Self-advocate, South London.)

“I am a Mum on my own. Only having a phone call from my support worker upsets me. It’s just not the same as having the emotional support when someone comes in. You know you just can’t get things off your chest in the same way. It’s really hard. There are days when I get really upset and I end up in tears.” (Self-advocate. Bognor Regis.)

Seeding a better future.

The following stories came from the group discussions where people explored ideas together:

“I don’t know what it is like in other areas but some of the social workers in our area just don’t take us seriously enough. We are ignored – it feels like they don’t listen. Social care in the future should make sure people really are listened to.” (Self-advocate, Wirall.)

“We need more support staff – this would make social care better.” (Self-advocate, Lancashire)

“Social workers only help us when things are really wrong – we need help planning for our future to stop things going wrong.” (Self-advocate, Wirall.)

“I feel like in the same way me and friends have come together to create ‘We Are All Able’ – more people should be supported to do this. Some money and support may be needed to help people get started – then we can just get on with it. We don’t all need lots of paid support.” (Self-advocate, Wirall.)

“Living on my own I was facing loads of challenges. I was really stuck. Luckily my friend contacted the local Labour coronavirus volunteer group. Now Rachel has started shopping for me three days a week, photographing my letters to send to my friend and doing my gas meter top ups for me. She has said she can help me a bit after this b****y virus has gone as well.” (Self-advocate, London)

Drawing out the themes.

- Community volunteers have offered essential support to the lives of many people during this pandemic. Moving forward, Social Care organisations need to recognise the importance of, and remove the barriers to, local people offering their time and skills.
- Having a mild learning disability/autism doesn’t mean you don’t need support. It does mean that both professional and community support needs to be responsive to people’s different capacities.
- There needs to be greater understanding from people offering services, from supermarkets to the police, that some people have invisible disabilities which reduce their ability to respond to new requirements.

- Some local councils have adapted rapidly to the new context to ensure a flexible response to offering support. Going forward we can learn from these examples.
- For many people family connections are very important in their lives. Support needs to recognise this.
- Social care needs to be working upstream to help people cope not just dealing with crisis.
- Social care in the future should encourage the street/neighbours connections that have been created during Covid-19 to continue.
- Support workers need to be valued in order for the right people to be recruited and for people to receive the support they require.
- Mobile data and the necessary equipment are key to supporting people to connect now and in the future. Data should be freely available to all.



* Paradigm is a values-based practice development agency working mostly in the field of learning disability. The main focus of its recent work has been revaluing the role of Direct Support Workers through developing the Gr8 Support Movement.

Many encouraging examples of what constitutes Gr8 Support are shared among support workers at <https://paradigm-uk.org/stories-of-gr8support/>

During the Covid crisis, it has also been facilitating telephone and internet connections among potentially isolated adults with learning disabilities. The quotes here come from these conversations.