



Survey on what happens after lockdown

Final Report

8 July 2020

Introduction

This report details the responses received to a north-west survey on how services should continue after lockdown has been lifted.

The survey was created using the online platform Survey Monkey and was open for three weeks, during which time 112 people completed it:

	Responses	
Self-advocates	58%	64
Family members	42%	46

Respondents lived in the following areas:

	Responses	
Greater Merseyside	13%	15
Greater Manchester	32%	36
Cheshire	9%	10
Lancashire	19%	21
Cumbria	3%	3
Other	24%	27

Respondents from outside the north-west were located in places such as Tyne and Wear, North Yorkshire, Sunderland, Teesside, Brighouse, Durham, Derbyshire, Essex, Lincolnshire, Dorset and London.

What People Said

People were asked if there were some things that had changed they would actually like to keep. Common changes mentioned by lots of people include Zoom / video calls to friends and family, GP consultations via video calls, neighbours helping neighbours, regular updates from Pathways Associates, voluntary groups supplying hot meals and not having to go to a day centre. Individuals also commented:

“He didn't like college and he doesn't miss it all. He said he was bored and unhappy there and we didn't know this.”

“Everything being available on zoom [as] going on public transport is very hard for me. For the first time in my life I don't feel excluded from services and social scenarios.”

“[The ban on] handshakes and hugs should be kept as some people are huggers.”

“My eldest likes to wear masks when out as they hide her face, and give her more confidence. With others wearing them, she will not stand out as much.”

"My son... has been in hospital for around 7 months. Before lock down came into effect I was visiting him around 4-5 days a week so this experience has been very upsetting... He has always struggled with using phones which is common with people with autism. Since lock down we have had contact via video calls and when encouraged [he] has done great. Because this 7 month period has been the only time he has been in hospital, we haven't had to put too much emphasis on him making phone calls. But now he is managing to use video messaging and it is something we will continue to do when he is out of hospital. So the video calls are something I would very much keep."

When people were asked what they have missed the most, many mentioned access to accessible information / easy read, being active, attending meetings with Pathways, school, respite outings, being at work, volunteering and face-to-face contact. Individuals also said:

“Daughter does not use [Zoom] and misses meeting her friends and carrying out activities in the real world. She has clear ideas about activities such as her dance group, drama etc taking place with her friends and things like Zoom do not interest her. She sees things like that as taking place at her home which is not what she wants.”

“My son used to have a therapeutic paid job - this gave him somewhere to go in his Motability car and a purpose for his personal assistant team every day... this ended with the lock down and is unlikely to restart following easing of lockdown - the risk to my son is too great.”

“[I have mostly missed] my two ASD children without EHCPs being in school. They learn better with that routine, although the eldest can get sensory overload in crowds (corridors & lunch hall - she has passes to help). My ASD with EHCP has attended (standard term time only - our choice) and has been able to work and enjoy other activities, while being kept safe and carrying out lots of handwashing!”

"Life for my son has been highly restricted since lockdown. He lives in a residential care home."

"Updates for people who can use IT are good, but concerned that we have not reached out to enough people who do not have IT skills or are supported to access them."

"Since my volunteering stopped I've had nothing to do."

We asked how we can make sure co-production still happens. Individuals commented:

"Bring back the national forum."

"Ensuring that we are included in any online meetings etc"

"Lots of zoom meetings (keep them short so they are do-able). You can have them more often. Keep asking us what we think or how it has been for us and we will keep telling you. Make sure that information is easy read so that we have a chance of getting involved."

"Involve us in lots of ways, remember not everyone is online, not everyone feels comfortable using Zoom."

"I don't use Zoom but if you want to know what I want or my thoughts on anything call me on the phone and ask me - or do surveys like these to find out what I want but I will need someone to support me to fill them."

"It doesn't happen in Cheshire East - hope anything you do can help with that. Could we work with regional ADASS & LGA?"

"It doesn't feel like it happened before the lockdown. No one seems to listen to people with autism but without an LD who have mental health issues."

"Not convinced Co-production is actually happening at present as decisions have been taken that impacts negatively on families and self-advocates."

"This is a very big question and requires ALL officials and functionaries to recognise, understand and put into practice that co-production is not something they do to us, often after the event, but something we have an equal say and full partnership in from inception all the way through to delivery. NOTHING about us, without us!"

"We can use online ways of doing things. If we can organise quizzes and games nights we can organise themed meetings about important things too. It would be a bad move to go back to services deciding everything without us. After all they must be meeting using the internet anyway so why not just include us?"

“We need to make sure that rights of people with learning disabilities are maintained. The role of Central Government has been very strong in lockdown. We need to ensure grass roots organisations are supported so that their voices and those of families can still be heard.”

We asked how we can make sure people we cannot visit are safe and being treated well. Many people mentioned audit checks, monitoring, ensuring staff are using PPE and contact via WhatsApp, telephone calls, video calls, email and Facetime.

Individuals also said:

“Allow people to be able to use their mobile devices to keep in touch with the outside world”

“Encouraging the idea of an independent 'circle of support' meeting... which could be recorded either in writing or via mobile phone if permission given by all involved. A copy could then be used to evidence that people are safe and being treated well.”

“Good question; my disabled sister is unable to verbalise her concerns about things that she's not happy about and when I ask staff, the response is 'she is fine’”

“I do feel like the government forgot us. There is a lot of talk about people who are clinically vulnerable to the virus. That doesn't include me but I am still vulnerable and I am still disabled and suddenly I can't access the services I need because I'm not clinically vulnerable to the virus. I agree those shielding need services first, but it is like everyone else with a disability was suddenly forgotten.”

“I will always ask [my son] if everything is ok and he tells me. If there has been any problems with his behaviour or say if he hasn't slept well it will be the first thing he tells me. So it's about keeping good communication and trust. He knows if he has any concerns he can trust me to help and support. If all I have left is 'phone calls and Skype, I use the tools I have. But that doesn't mean the situation shouldn't change.”

“Services need to be checking with people and not believing what they are told without seeing people themselves when we are worried. No access to the internet and smart phones in 2020 is ridiculous and needs sorting out now”

“My nephew in a long term residential mental health hospital sees his mum on patient rounds via online... Why not a zoom coffee & chat with those and wider family?”

“We need to ensure that CQC inspections resume.”

"I think it would be good to set up an equivalent of CTRs for care homes and also local quality inspections."

"We need to make sure that people in ATUs have access at all times to independent organisations who can make sure their voices are heard via social media like Zoom. We may need to legislate on this, as ATUs can currently deny people with learning disabilities the right to contact their families or other external organisations. We also need people to be checked on for their physical health and wellbeing regularly. One of the disturbing aspects of lockdown is the lack of control residents have over who is admitted to care homes."

"There is no reason why people can't be supported to chat to us on zoom or something like that. Hold the providers to account if they aren't helping people to connect with family and friends. Ask for feedback on how people are doing, if they are in an ATU then they should be making progress not just existing. Ask the providers to report on what approaches and strategies they are using and how the individual has got on with these, then we can chat to the individual about how they feel and if they feel it is helping. We just have to be able to contact people - it's not acceptable to say that people can't have contact with the world in this day and age."

"Testing for supported living and domiciliary care need to be routinely introduced."

"We shouldn't not be allowed to visit. Only by visiting can we ensure that they are safe and being treated well."

We asked what people wanted short breaks and things to do in the day to look like in the future. Individuals said:

"Autism only things including those without support workers or social services involvement."

"Being unemployed, I'd like to assist those of us who can live independent of outside help. Opportunities to support our communities, for example..."

"I would like to see less emphasis on day centre / coach trips for poorly people and more effort put into supporting individuals to lead truly independent lives."

"Everything to be easy read and accessible for people with disabilities "

"I want them to look the same as they did before - I go out with someone to do the things I enjoy"

"I want to get back to going to meetings with friends and bosses in Preston and Accrington"

“If there is less crowding / more space for crowds to spread out, then my teen who struggles in crowds can manage them for longer before having a sensory overload and subsequent sensory shutdown (her vision goes), or not get them.”

"It may be that short breaks might have to be organised so that bubbles of people who are in close contact regularly use those services. There will need to be careful hygiene measures in place at all times and testing before a short break takes place. It may be that we increase different models for short breaks, such as shared lives models?"

“More flexible, it has been great that my daughter has been able to have her college 1:1 support at home. She has kept involved with her friends and up to date with her work plus it has given me a break to work too because she is busy and happy. As long as short breaks are what she wants and help her not be so dependent on me perhaps I am not the right person to answer this on her behalf. She needs time to be independent from me to live her life.”

“More stuff in the community not at day centres”

“Need to be more responsive to the needs of individual, rather than expect people to fit into services that are not sustainable if there is a reoccurrence of Covid 19 or any other restriction.”

“Our short breaks (respite care) should be in locations professionals would choose to go to with their families”

"Lots of choice and flexibility to be able to do it because I want to do it, not because the support is available. I think a mix of doing things in groups and on my own. The important thing is to have a choice and it's my choice. A short break should feel like a holiday not a trip to the dentist. Shared lives can be a good experience, just hanging out with someone I get on with and we decide together what we want to do. One time we might want to go to the cinema, another time we just chill at home, or out shopping.”

“Allow people with a personal budget to use it creatively. Maybe a PA/carer is not always the best way to meet needs. Perhaps a gym pass or laptop or adapted bike will be more appropriate?”

Deaths of people with learning disabilities receiving care more than doubled during lockdown. We asked what more can be done to keep people healthy and safe. Individuals said:

“Better providers - more integration into real world”

“Do health checks every month”

“Ensure that all premature deaths are FULLY investigated and that the investigation process is open to our scrutiny.”

“Make DNR unlawful”

“Better testing, isolating and PPE.”

“If people live together in small group homes and care homes with a staff team then clearly the risk of catching the virus is increased. I do understand that many people would choose to live like this, but my son lives in his own house with his own dedicated staff team because he does not like to be in groups of people with a learning disability. We think that his lifestyle has helped to keep him virus free so far...but the virus situation is still very scary for all involved.”

“Make sure that people with disabilities understand what is happening during the time that they are unwell, and that they are safe”

“People with learning disabilities need to be well- supported by GPs at all times. They need to be checked and monitored and community learning disability nurse numbers need to be increased.”

“Some people, like my son, have been well- supported, but for others, access to community- based GP services has not been great. Also, there needs to be access to community- based treatments like access to oxygen and IV drugs , which will require changes to how people are trained and supported. We also need to ensure that people with learning disabilities are supported throughout their hospital experiences all the way through admission, not just at the assessment phase, but throughout treatment, by people who have the skills to understand their communication and medical history, instead of being separated from that support after admission. It is also vital that LD liaison nurses are re- named as nurse specialists and we need them to not be a token presence in hospitals. One LD liaison nurse covering a group of hospitals is simply not good enough and perpetuates health inequalities.”

“Personally I feel more practical accurate guidance in an easy read version at the beginning of the Lockdown would HAVE helped people to stay safe.”

“Government & GPs surgeries acting together & contacting those they felt were vulnerable sooner. I can only speak for myself but it was weeks into the lockdown before I was advise by letter I should be shielding - which I already was. I had to fill in government forms to be allocated food parcels - 3 x's before I got it right (being dyslexic), fortunately my sister found the right telephone no to get me on the Tesco Vulnerable Customer Priority Delivery - with not much joy but she did get us some Asda Delivery slots!”

"The focus seemed to be on the NHS Hospitals and later on care homes for the elderly when resources were limited, overlooking anyone with additional needs that wasn't in those settings when it comes to getting tests and having suitable PPE. "

"This disgraceful statistic needs addressing by government and strategies put in place to ensure that LD people get the right support regardless of financial implications. 10 years of austerity must NOT be repeated."

"I receive text messages from my local surgery. They are really helpful. I had to have a blood test during lockdown; my surgery sent me information beforehand. This helped me a lot."

"Value all life - realise that those with LD +/- Autism are just as vulnerable as the elderly and that the same level of precautions should be taken. Promote health checks so that any underlying condition can be identified and recorded. Ensure that monitoring is carried out and treatment given as needed. Ensure that MH and self-neglect are included in risk and health assessments. Ensure that specialist provision is available to support identified needs and that the onus isn't on the individual to sort out all this."

"Make sure people with LD understand about hygiene and keeping clean and why this is important. Info in easy read with videos and audio to go with it so I can understand all the complicated info that is being sent out. Keep the info basic and only give me the vital info I need, not waffle."

We asked people what support do children, young people and their parents need during this time. Individuals said:

"A comprehensive, free, online learning programme based on the national curriculum. It must be able to detail precisely how much work the learner has done each day, like IXL and Duolingo already do."

"A shoulder and an ear to talk to and listen to, they need to have people caring for them and services to be more helpful around them "

"Accurate, reliable, consistent, usable information and somewhere to go to talk about it if need be."

"Activities for children and parents to do with their children. Knowing there is someone they can contact by phone or message if they feel they are not coping"

"Encouragement to keep in contact and the different ways we can do this via video messaging etc. Maybe the hospital putting aside times through the day where they could ring family and encourage the child/ young person to chat with family. At times [my son] doesn't seem too keen on chatting to us but

then sometimes he has a big smile and will ask me loads of questions about where I am and I am able to show him because of video messaging. Or he'll ask me about his own concerns. Just to see him smiling and also asking me relevant questions and me being able to answer and show him is reassuring for me..."

"Not my current experience but it must be so tough for many families. Decent advice on managing behaviours that challenge - CBF good. Ideas re activities & learning - resources online & 'real' for people without internet. Ability to spend PBs on tech - iPads & smartphones to access practical advice, help & things to do. Emotional/mental wellbeing support at the end of a phone/online groups (eg Camerados Spoon Rooms). Much of this applies to adults as well."

"Clear rules over guidance for PA staff working."

"Our family has never needed much support, and that hasn't changed. We do use public transport, so making sure there is space and it is not over crowded would help us. This probably needs feeding back to transport sector. "

"Regular updates and video contact. As a parent it has been very difficult trying to cope - feeling alone"

"Young people and children need support to be helped to maintain hand hygiene etc and to be de-sensitised to wearing masks if necessary. There will be some, like my son, who would find it impossible to fully cooperate with these requirements, so it is about minimising risks for them by organising the environment around them. Children and young people need supportive, easy ways of understanding about Covid 19. This could be through film, photos, art as well as easy read. Some, like my son, cannot understand easy read. Parents need accurate information, preferably from health professionals, about local risks on Covid 19 to make informed decisions. It may be that there needs to be more individualised education opportunities for those whose health is particularly vulnerable, for some time to come. I am concerned that so many children and young people are not getting their special educational needs met. Also that children who are looked after are not receiving the help they really need right now."

"They need as a minimum to be kept informed. Most families have just been left to get on with it. They need transparency when it comes to arrangements concerning them, and should ideally be involved in decisions about their care, schooling and services. I feel as if we have gone backwards in this respect and the Coronavirus Act has made things worse."

"Help from counsellors, family liaison or family support people, zoom calls with teachers and set activities to keep everyone occupied. It is very difficult as support they need like respite and home support by a person can't happen so

they are missing out on all the usual support. It's very hard for the children not seeing their friends and carers; it is also hard for parents having to deal with children's behaviour which is likely to be worse at this time."

People were asked what they wanted to tell the bosses about how they'd like support to be organised as restrictions are lifted. Individuals said:

"All support workers need to have any equipment they need and be ready to offer support again as soon as it is safe."

"As a family it is not a good time to ask. My 2 nephews (Greater Manchester), both with complex needs after a long stay on a hospital mental health ward have been moved a long distance from their home. They have gone to a different residential private hospital. Both have wanted a home. Family have wanted them to have a home nearby to family. One has been moved a few days before his birthday. It has cost a fortune to keep them hospitalised & they & family have not been listened too. I would like to say to the commissioners who signed that off, why did you not commission a new service to meet their needs in your local area? They have been known to, and under care of social services for many years. With all the promises of transforming care and homes not hospitals, why are you in the position in 2020 of funding placements that add stress because of the distance, ignoring family concerns?"

"As a family that includes a person who has a learning disability and uses direct payments we would like to be kept up to date with local fact-based information and advice regarding the virus."

"Coronavirus Act repealed and care services and duties put back in place by local authorities and government"

"Don't send my learning disabled son any more letters in Local Government speak."

"Each person should be treated as an individual, their likes & dislikes built into their care & support."

"Contracts with care agencies should always have the individual client @ the heart of the service - currently agencies dictate the service an individual client gets (e.g. it seems to be built into contracts there can be a 2hr window for visits - people have told me they have had tea time (evening meal) call & bedtime call back to back too. There are many complaints that for meal time visits agency staff will do Microwave meals (claiming they haven't the time)."

"I'd like there to be individual conversations with families and care providers about the right support for individuals- right support in the right place. I'd like

the Government to be challenged about the invisibility of people with learning disabilities in the response to this pandemic.”

“Make sure that people with disabilities are given easy read information “

“Pay user-led organisations to deliver the necessary advocacy and support. We can look after our own if we are given the resources.”

“Personalised, come and ask me what makes sense don't assume you know it. Don't go back to old ways of working and embrace the gift model again. If you can meet online to plan, you can involve us”

“Some LAs have lifted restrictions on what people can spend PBs on - need continued flexibility that gives people choice & control to live the lives they want. Simplify processes, especially financial audits. Trust people more to make decisions for themselves. Work across organisational boundaries without making a song and dance or arguing about who's going to pay for things. Local councillors need to understand much more about people's lives/social care/how it works. More connections locally - especially to universal things - inclusion!”

“To remember that other areas of health matter are important too, e.g. routine, minor, such as physiotherapy, podiatry, scans. That we need to know the forward plan for schools ASAP so that we can prepare for it and look forward to it.”

“We need more staff in support services to be able to take the clients out without feeling scared. It shouldn't be just a one person job, they should be able to partner up with another colleague when there is more than one client with them.”

"Help to get a flat and be more independent...lockdown was a long time with my parents.”

“You need to listen to us - we are the experts in our own care. Treat us with respect.”

“Flexible, so the choice is with us. I don't want my social life to be arranged around workers' shifts. Good information in easy read should be ALWAYS be used, why would you put information about us in a way that we can't understand? Keeping us in forever is not OK; we all have to be allowed to choose what risks we take.”

"ALL Info in Easy Read - keep it simple. A promise that you will START with an Easy Read summary and NOT just bolt it on at the end MAKE THIS YOUR STARTING POINT and not an afterthought also different versions of info on video & audio - ALSO remember NOT everyone is online and can't do things

digitally so don't forget about us as this will exclude me. Learning new things take time and we all need to be patient when doing things differently in these times."

"There should be more hours made available for those in the vulnerable section who live independently, to ensure their mental health and well-being issues are being addressed. More money for local activity groups that do not cost much, as many vulnerable people do not have an income and survive on benefits. Clubs that teach them basic cooking skills (maybe cooking a meal to eat for their lunch/tea) and how to look after themselves, both physically and mentally. Free access to technology and training on how to use it to keep in touch with friends and family (2nd hand or donated phones/tablets/iPads?) - another 'club' which could be set up."

People were then asked if there is anything they are really worried about. Individuals said:

"A second wave as I continually see people breaking rules and not social distancing"

"Continued self-isolation "

"Going back to having to fight every single day to show people self-advocacy works!"

"Government putting politics and economy before health. "

"I am really worried that there could be spikes of infection until a vaccine is found - if it ever is - and that the isolation is having a big negative effect on the mental health of people with learning disabilities and their families. So many people are being isolated from each other."

"My son catching the virus...the thought of him dying alone in hospital keeps me awake at night...."

"No lessons being learnt or people jumping to assumptions and making changes before really understanding what changes are best to make happen."

"Not being able to go back to work."

"Not having the facilities to get involved with what Pathways are doing day-to-day."

"People's deaths due to DNR notices being covered up"

"The Coronavirus Act staying in place and draconian measures used to reduce services"

“The culture of the NHS, I do not trust doctors to make good decisions about life and death for people with a learning disability - or disabled people generally. I do not believe the NHS values all lives equally and that really frightens me for my daughter and friends - and for me as I get older”

“Therapy and assessments being further delayed”

“That our family members have safe care. Both have experienced poor care including physical assaults by staff in private residential hospital/ failure to meet needs spot signs of serious illness in the past. Naturally this means as a family we worry if they will lose their life due to poor care. “

“To open the home too quickly and risk any infection being brought in to the home by others”

“The same thing we are always worried about. There is no mental health service for people with autism without an LD but with mental health issues. My son does not have an LD but as the mental health team keep saying "we don't know anything about autism", he has been taken on by the LD team. But that has not been helpful as they are not used to working with people who are autistic but don't have an LD. There is no service for our son.”

“My daughter has a rare genetic condition. 2 weeks ago an 11 year old girl with the same condition as her died with Covid. She had hardly any symptoms. I don't think people understand how worrying it is. There are only about 100 people with the same condition as my daughter. This is my big worry. Things are going to fast that I wouldn't be happy with her in college at 2 metres distance yet it is looking like by Sept there will be no distancing at all.”

“My care charge is £94, which is way more than I can afford because things like needing a car or having a lot of food go off because I am forgetful so it counts even though they are because of my disability. They also count my expenses as if I were a single person but I have four children so if I need takeaway because I can't cook it's £50, not £10. I am very worried about how I will pay this much when I start driving again and still don't have work to make up for it.”

“I am really worried about my family member. I don't really know how they are at the moment. I've lost my important role as their friend, supporter and advocate as my contact has been severely restricted due to Covid. As they don't really understand why they're not seeing me, I am concerned that re-establishing our relationship after this crisis is over may be difficult.”

Fewer people have been admitted to long-stay hospitals as inpatients during the crisis. So we asked how we can make sure people carry on living in the community and do not have to go into hospital. Individuals said:

“Make it just as hard as it is now to section people and keep developing good community based support with us!”

“By providing the right support for each individual “

“By stressing the necessity of early intervention, thereby ensuring that people don't reach crisis point”

“Fund decent care packages - home not hospitals - with trained, well paid staff. Despite current distance restrictions they should encourage community engagement. Accountability with links to specialist health services. “

“Get good community support in place. Try other strategies before sending them to hospital. Work together as a team”

“Give people more / better support at the first signs of difficulties. Makes sense on all fronts given the distress and financial costs that could be avoided. Check up regularly on people most at risk. Enable them to be connected, to contribute to their local community & the other wellbeing things. Stop medicating/over-medicating and talk more. Give families & support staff the right info & advice about managing difficult situations & behaviour that challenges. “

“For [my son] it has been about consistency of placement, medication and most importantly carers who are familiar, experienced, caring and empathetic. When in the community he had 3 day and night respite provision and I feel he struggled with the inconsistency of agency staff. Forming trust and bonds with the people caring for him is very important to him as it would be for most of us. As I have already said and have seen evidence of at his current placement, he thrives in a familiar, friendly environment.”

“I think it is a good thing fewer people have been admitted to ATUs. We need far, far better capacity to develop community- based responses though. We need more than intensive support teams as we need the community mental health support for people with learning disabilities to be far stronger. 1We might need community- based support in their own homes, day and respite care services aimed at people who will need higher levels of support, better training in supporting people both in ordinary day services, and support and training for families. It needs an integrated mental health service approach for people with learning disabilities and autism.”

“Keep experts by experience involved”

“My son needs more support from trained professionals who know how to work with young autistic people with mental health issues. There needs to be a one-stop shop for autistic people where they can go for help with their mental health, social activities, meeting others etc. Carers also need support.

There is so little out there for autistic people without an LD. They are being neglected. Many are ending up in social care provision because the right help and support isn't available in the community.”

“Plan, plan and plan again. Make sure there is a plan b,c and d available with a budget attached. Listening to what people are telling you makes sense. Don't wait till things are too progressed. Forget how things have always operated and open your mind to new possibilities - if nothing else we have learned so much in this period.”

“We could close down the hospitals! They should not be an option for learning disability”

“The long term support of people with extra needs has to be a national programme - recognised as providing a service to all of a high quality...that provides important employment for almost a million professionals and care staff teams...that enable lots of local community based employment opportunities that bring huge benefit to local communities for all involved.”

“We need to look at what services are making a difference to keeping the person well and safe in the community. There is a major risk that numbers will dramatically increase because of impact of self-isolation.”

“Follow the care guide by the National Autistic Taskforce. It is designed for meeting needs so people don't end up in ATUs. Consider that ATUs are such a bad place that they might be causing the behaviour problems.”

“By assessing their needs more and alerting behaviour. Assessments are not being met such as Autism Assessments and Sensory Assessments which would make a difference to this area. More action is needed to get the correct assessments from a young age so it follows through Adult life.