

**FORGOTTEN FAMILIES ZOOM MEETING – JUNE 22ND 2020**

**Consultation For Family Members With Loved Ones in Residential Care, Including ATUs**

**There were at 22 family members who kindly contributed towards this consultation meeting, which included at least 15 members who discussed largely negative experiences; 4 who discussed largely positive experiences; and 3 who conveyed both positive and negative.**

**Themes**

***Most difficult/hardest thing about loved ones being in residential care during Covid-19 lockdown:***

* No voice and no status for people with disabilities, learning disabilities and their families. A belief that this is not simply Covid-19 specific, but is an endemic problem.
* A strong feeling and belief that the government doesn’t care about the needs of people with Learning Disabilities and with Disabilities in general.
* Family members given no information about what is happening in hospitals and in-patient settings.
* Significant deterioration in mental health and physical health of loved ones in care.
* Loved one being given diagnosis without family consultation, resulting in treatment programmes that are not agreed with and are potentially detrimental.
* Self-harming increasing due to increased anxiety and mental health difficulties.
* Not allowing the young people out of the settings and reducing contact with loved ones even further, to both contain the virus spread, but also a difficulty understanding social distancing.
* CCGs being completely obstructive regarding an alternative care package which would allow loved ones to leave their residential setting and come home during lockdown.
* Loved one’s routine has completely changed; this has led to depression and withdrawal from life due to an absolute reliance on routine.
* Loved one given no opportunity to take part in Eid celebrations and to join in any of ours. We don’t feel that settings are taking BAME needs into consideration.
* Confusion and conflict regarding the advice being given and the way that guidance is being carried out.
* Even further lockdown leads to a highly concerning vicious cycle for our loved one. Lack of exercise and fresh air leads to a lethargy and depression. This leads to over-eating on “comfort foods”. Putting on more weight and the resultant negative knock-on effect on health.
* Currently do have a good provider, but I can see that they are under intense stress and pressure. We do see things that are not right, but we’re scared to raise any issues in case it leads to a breakdown in the placement.
* Using Covid-19 as an excuse for reducing contact with family members even further; no visits and locked-indoors all day.
* Lack of understanding of the condition of Demand Avoidance (PDA); and, instead, viewed by staff members as the individual just being awkward, difficult and challenging.
* Not having social support help.
* Not being able to go shopping.
* Not having the opportunity to have loved one at home.
* Loss of activities and routines that had taken so long to establish.
* Confusion for loved ones, as they struggle to understand Covid-19 and social distance.
* The long-term emotional impact.
* Not understanding social distancing from close family members.
* Using Covid-19 as an excuse to lockdown even further and to keep families at a distance.
* Not seeing loved ones.
* Families have been silenced; there seems to be relatively few complaints, which may be partly due to just accepting poor care as one of the consequences of Covid-19, but also the possibility that families don’t dare to complain in case their loved ones experience even more privation.

**Quotes:**

*“My son is going downhill so fast. He has such high anxiety that he chews all of his t-shirts and now they’re hanging off him. I’m not allowed to see him and he doesn’t get out. We disagree with their diagnosis and we know they don’t believe in what we say. He has PDA. Obviously, I’m missing him and can’t get access.”*

*“We’ve all been experiencing such stress and anxiety. My son is in a care home and he’s non-verbal. No one is trying to communicate with him. No attempts at social stories or anything to help him understand. It’s been so hard not seeing him. He came home once and he loves his kisses and cuddles, so it’s difficult for him to understand social distancing and why we are wearing a mask.”*

*“People with Learning Difficulties living in residential settings should not be kept away from loved ones and family members. I don’t know the best way to do it – testing, quarantine? But they should be able to work it out.”*

*“I don’t think we have yet seen the long-term impact of this on our loved ones and wider family members. This experience is traumatising for our loved ones and traumatic for the family.”*

*“My D. was in hospital under a section 3. She was released just before Covid-19 started and she was given a flat on her own – without any support. My worry is not Covid-19, but the fact that my daughter is left in a flat on her own; left to go downhill and I have to watch it.”*

*“My big fear is that my son will deteriorate further as he is in the wrong environment. My son knows what he needs and he is very verbal. He knows that he is in the wrong place and that the staff disregard him. His wishes and feelings continue to get ignored. He wants to live in his own place. The Social Worker has repeatedly said that my son has never said that he doesn’t like it where he is; but he has told people in meetings a lot of times. He used to be so able. He passed his exams at school. He used to enjoy all of his different activities. He has earned certificates and has done everything. The system has just worn him down and he’s lost his skills. He’s lost his passion for life.”*

*“This government do not take into account, and I include the public face of the NHS in this, the needs of our children with LD or any other disabilities. We have no voice in what happens. In either a legal way or any other way.”*

*“I’ve asked for reasonable adjustments… sit in the car to see him but they won’t let me see him. Apart from that he hasn’t been out at all. Been there for 14/15 months he hasn’t been out more than a dozen times. They don’t understand him. They put restrictions on him. This goes totally against his PDA. They are not working to his diagnosis. Everything they do is wrong and I am missing him and he can’t get out to see me. His mental health is going downhill and he is frightened because of the corona virus.”*

*“My son has only been out in the last two weeks. Staff refused to take him out before that because of the difficulties he would have with social distancing. He has started self-harming worse than before. He doesn’t understand covid. I haven’t been to visit for 18 weeks. They brought him to Islington two weeks ago. He refused to go back… he had an hour on the ground. People thought he was having a fit but he was refusing to go. They wouldn’t allow us to visit. It has been really difficult. Also have J. who is 12 and refuses to leave the house. Suffering extreme anxiety. Can’t complain too much. Those with children in ATUs ….. they are suffering so much.”*

*“My son Jamie was in residential home in own flat but when we saw the way covid was going, we decided to bring him home to become full time carers. I saw that there would be no visits, that he would be locked indoors all day. Incredibly difficult for him to tolerate this. Not having any help has been hard and not being able to go shopping.”*

*“T. has a shared care package… half the time at home, half the time in residential. Saw it coming, asked for extra time at home. It was refused. Since Sunday 22nd March he has stayed in care home full time. CCG has been completely obstructive in allowing an alternative care package to allow T. to come home. We have been able to see him purely because his bedroom window is on public land. He needs 24/7 … up until today he has been in his room all the time with someone coming in every hour. Masked faces coming in and out. We are fortunate that we can afford to put in place a care package at home. CCG will reluctantly agree to a BI meeting to try and take this forward. I have contacted my MP.”*

*“My son is 40 miles away. 4 years ago he was discharged from ATU. Took a long time to settle into residential home. He did settle well. He has lost all his activities, we haven’t seen him since lockdown began. He used to come home, go on holiday, we visited him. The Care home have said that they will not change anything until government guidelines on care homes change. He’s sitting watching TV all day. The long term effects worry me. How do we get him back to his old self?”*

*“My son is in supported living about 15 minutes away in car. I cannot visit him. All routine broken down, he is depressed. He visits home but police have to be called to remove him from our home and take him back. No shopping, swimming pool….. incidents increased a lot. 2/3/4 hours he is on the floor, given PRN, and that is increased. Police been called a lot of time to deal with this. Police use handcuff to him and say he has to go into hospital again – ATU. My son didn’t sleep the whole night. Broken the fridge, new TV, …. He keeps breaking them….. all radiators falling off from wall. Camera monitoring us when we are together. Telephone calls on loudspeaker. Parents blamed and safeguarded. Very stressful, I cannot sleep. It’s awful.”*

*“My son, aged 19, is in a residential setting. He should have moved out in February. Failing setting should have moved but everything has come to standstill. He is non-verbal. No one has explained to him what is happening … I’ve asked for lots of things … social distancing…. We asked to see him with Eid coming up…. They had VE party… but we are told no. Nothing done for Eid. I’ve increased facetime …. Been extremely hard … he did come home for home visit. He was expected to wear amask and he couldn’t and couldn’t keep to 2 metre distance. Care in general not catering for BAME needs. Lots of things going amiss.”*

*“My daughter is still in ATU after 14 years. Although we couldn’t see her, we saw her for first time last week. No fresh air or exercise, very unhealthy diets … compensate with food. Also medication can make them put on weight. And these are risk factors for Covid. She got the virus, and she only got that because she is in the hospital. She is OK but if she was at home, she wouldn’t have got it. My concern is that she is at higher risk in ATU than she would be at home. Staff coming in and out. What if our loved ones get physically unwell? They are at higher risk because lifestyle in hospital is so unhealthy.”*

*“I also support several families with loved ones in ATUs and hearing shocking stories of how they are being treated. People being unlawfully excluded. Human rights being abused on daily basis. My son was discharged in December and we have an excellent provider. I brought him home to me at beginning of lockdown and LA withdrew his support. I live in a one bedroom flat. Very luckily his provider brought us shopping. The LA has not paid them to do this. How long will a good small providers survive if LAs do not pay them?”*

**Anything that has really helped and can be shared to possibly help others**

**Themes:**

* Provider does genuinely want to hear about what isn’t going well.
* Found person could trust to talk to within the provider organisation and that has given strength.
* Being able to bring loved one home.
* Being able to contact our MP and be listened to.
* Finding the right person to talk to about the specific issue of concern.
* Staff are caring and compassionate.
* Local Authority putting more money into Direct Payment budgets to cover extra costs.
* Care provider sees parent/family members as part of the team.
* Staff who genuinely care and go the extra mile, creatively, to keep loved-one happy and occupied.
* Continuation of Care and Treatment Reviews has really helped.
* Larger provider has the resources to set up an outdoor café, where the users can go and social distance.
* Setting up of family helpline, targeting any families who want to call and also putting out explanations of any government directives.

**Quotes:**

*“One thing I like about my care provider I can talk to them. Any issues I can raise and they are amazing at coming back to me with ideas and their attempts to find a solution.”*

*“Sometimes you are frightened to rock the boat, but finding the right person to trust to talk with. That has given me the strength to carry on fighting. I have found during this period thinking I can’t go on doing this. Need to find trusted person to talk to.”*

*“I am very lucky. My son lives independently in own bungalow. Staff are very caring and compassionate. There are some issues. But one of the things I really like about my care provider is that I can talk to them. I don’t want to rock the boat, but they try and find a solution. A lot of care providers lack that empathy for parents and families. They need that wider understanding about parents being part of the team.”*

*“Good support…. we are having some difficulties. My son has PMLD and staff have been incredibly creative and have kept in touch. They genuinely care and have gone to great efforts: zoom sessions, meals, dressing up etc.”*

*“I have been doing CTRs – they have carried on throughout this and in the hospitals where we found they weren’t quickly setting up video calling or skype etc we made sure they did. We highlighted it and put in on an action place and they did make changes. That made a big difference to a lot of people.”*

*“Many examples of bad practice and some examples of good practice. Doesn’t seem to be a space for us as families to share good practice. My daughter has fortunately been having some good practice but that is down to individual staff looking after her and/or provider. They have set up a day centre in the open air, using social distancing. This is so important to share. MPs need to know about these things. We need to get the voice across to the government and to the NHS.”*

*“We have been doing a family helpline so that any families having difficulties seeing loved ones can ring us and we can make it happen. We make sense of guidance in our setting. Easy simple read to explain guidance.”*

*“Although we haven’t had a chance to see our son, I feel a bit of a fraud because we have had some good experiences. The staff have been absolutely brilliant; getting him out and doing activities with him. I feel bad for other families because mine is a positive experience and I wanted to say that it can be done. There are some good places and practices.”*

*“It has been really difficult because I’m missing my son, however the staff have been fantastic – video calls, communication on a daily basis. They have been amazing. Why is it that these other places can’t seem to do it? We know that there are some excellent care providers, so what is it that the others are doing differently?”*

*“My daughter is at home with me. That creates its own difficulties but not nearly as bad as what you are going through. So hard to make arrangements for everyone. I have been astonished at how few families through my work (with care provider) have raised concerns about seeing their loved ones.”*

*“My son wasn’t with a good provider before this one he is with now. He now has good provider who look after him well. I don’t want to raise anything as I don’t want to jeopardise where he is. I haven’t been able to see him. We skype 2 or 3 times a day. I feel the provider is under pressure. They are struggling with staff and it is a difficult time for providers and for us. We need to be aware of that.”*

**Fears and Concerns; Impact on you and your family, including mental well-being**

* Uncertainty about the future.
* No replacement/substitute for loss of activities.
* Loved-ones going mentally downhill, with anxiety and depression.
* Helplessness, without seeing an end to it.
* Long-term trauma for loved-ones and family.
* Total lack of support in local area.
* Physical threat to our loved-ones in hospital
* Fear that my loved-one will deteriorate further in the wrong care environment.
* Marginalisation of parents and family members.
* Lack of empathy, feeling, understanding from services.
* People with autism and OCD are particularly vulnerable as they often don’t get the right treatment anyway; but Covid-19 can make this so much worse, due to loss of routine and contamination phobias.
* Access to more typical healthcare; difficulty accessing GPs.
* Loss of access to therapeutic services – physio, OT, hydrotherapy, psychotherapy, etc.
* Loss of annual, regular health checks.

**Quotes:**

*“The uncertainty about the future. When will activities get back? There’s nothing to replace them. (our loved ones) are going downhill because they are bored. And providers who don’t make effort to provide alternative things. Don’t know what is going to happen next week or next month. We don’t get information from government, it keeps changing. They want to focus on getting back to work, getting things open, but those in care homes or supported living are almost forgotten about. And us as parents feel we can’t do anything about it and we can see no end of it.”*

*“There is a very serious physical threat to our loved ones in hospital. They are in vulnerable categories. The discrimination against our loved ones is appalling. My middle daughter had cancer at 13, was supposed to be shielding. She is now 23 and she goes out for walks in open air and it did her so much good. She is physically vulnerable but she coped by walking and seeing friends and they would keep the distance and she could do all of that because she wasn’t locked up. My daughter who was locked up couldn’t do any of that. It’s discrimination. Fresh air, sun… we know that helps our mental health. But they take this away unreasonably so. They could go out where they won’t see anyone. They are allowed to get away with this. My daughter in ATU was supposed to be discharged in March but that didn’t happen. I was told by my duaghter’s commissioner that there were others that should have been discharged but they weren’t. Things were bad before, but they are worse now. Other people in my daughters ATU have died. How many people in ATUs have died? And are those deaths related to Covid?”*

*“My concern is the welfare of my son. I haven’t seen him for over 12 weeks. Before lockdown the staff were stealing his toiletries… at the time when there were no loo rolls anywhere. I haven’t been there to see what is going on. I had a phone call on Saturday and he was saying he had broken his DVD and ripped his pillows. So for two nights he has had no pillows. We have been asking to see him in his garden for past two weeks. Apparently they are waiting to see if the landlord will agree to this! No communication for 12 weeks. Have seen member of staff today who said that the incident on Saturday was because he was asking for me. Last week there were 7 people in his property … he is going to a new provider… they (representatives from the old and the new provider) were all there, but we are not allowed in. I can go and sit in my friend’s garden, but I can’t go and sit in my son’s garden. He is in supported living. It doesn’t make any sense. I have asked for a BI meeting, been told that is too much to organise by social worker and she would have to do a capacity assessment. I think it is because it is the current provider is leaving and we won’t get to see him until he has moved. Definitely not working in his best interests. Who do we turn to for help?”*

*“I am concerned about people with OCD who are also autistic. Community mental health teams may not take into account their autism. I see phobias becoming much worse. They are at high risk of admission to hospital. I wonder if NHS England are aware and have a plan to address the issue.”*

*“… also annual health checks are done remotely. I think this is a really big problem. We were due to commence reduction in anti-psychotic medication, but this has not happened. Worried that our people will be at the back of the queue for things getting back to normal.”*

*“Fights that parents have and are completely dismissed. Psychiatrists will not listen to parents. My question for NHS England.. my son came out 19 months ago. I was promised they would start decreasing those drugs, but he is still on those drugs even now. He is always tired, can’t move properly. They won’t listen to me, but they listen to psychiatrists. They say my son should be on those drugs for life. Can NHS England …. Paying out thousands of pounds every day…. He will always have autism…. He will always self-harm. Drugs don’t make any difference so why give them to him? This is like his days in ATU… and no one is listening. Stop the prescribing of these medications. Stop this abuse of power. I am scared that in September that we will see the psychiatrist and she sees the amount of PRN he has been described and she says she was right.”*

**The Overall Key Themes Noted by the Zoom Observers, Including Anything Else Raised**

* **The family members’ experiences of alienation, disempowerment, lack of human care, confusion, maltreatment and mental well-being deterioration – which have been consistently raised prior to Covid-19 – have now all been significantly exacerbated by the Residential Home’s and ATU’s interpretation of lockdown.**
* **The family members’ increasing feelings and beliefs that local services, social services, residential services, ATUs, transforming care services, CCGs, National Health Services and CQC offer no priority to their at-risk loved ones; have no individual or unified strategies regarding Covid-19; and they will continue to be neglected, maltreated and forgotten about as the country comes out of lockdown.**
* **There are family members who do clearly experience some very good and even excellent practice regarding the care of their loved ones in residential care. Whilst it is impossible to generate true numbers within the consultations, these positive experiences appear to be by far in the minority and it is concerning that the voices that we do hear are at risk of being swamped.**

***The further points raised were often put in the form of questions:***

* Close family members – often the life-long carers - know their loved ones and young people better than anyone else. Why are their views not heard and not valued?; why are they disempowered?; why are they alienated and made to feel like the enemy?
* Some good practice has been described in terms of local health services ensuring that regular, necessary health checks and assessments are carried out. Why can’t these be arranged in the same way in residential settings, through GPs, community nurses, physios, OTs, Speech & Language Therapists, etc.?
* How many people in residential care and ATUs have become seriously ill and died from Covid-19?
* As mentioned above, some family members have experienced some excellent care and service responses to Covid-19 and lockdown. What stops other places, homes, agencies and services doing the same?
* Can we have accurate, easy-read information and access to individual-appropriate information, including the needs of all learning abilities?
* Where are transforming care in all of this?
* Where are the independent advocates?
* “The levels of anti-psychotic drugs given to our children is appalling.” Where is the scrutiny regarding drug prescription?
* Why aren’t all individuals coming out of ATUs offered a trauma assessment?
* “NHS England issue excellent guidance but there is no insistence on CCGs and/or Local Authority’s to follow this guidance. The guidance is then worthless.” Why?
* The Challenging Behaviour Foundation, National Autistic Society and Mencap – to name a few – all have valuable information and help that they have been putting out during this pandemic. How do we make sure that it reaches all of the appropriate areas of need and do better at joining services up?
* Why is that Best-Interest and Care & Treatment Review meetings appear to be often missed or put on hold during this lockdown period? With zoom and other similar technology, there could be a real opportunity for enhancing how these reviews are carried out.
* Can we have a template letter for writing to our MP?
* Is it possible for family members feeling isolated and disempowered to have a clear and easy route to challenge and complain about the treatment their loved ones are receiving?
* Can “Restorative Practice in Health” have a role in helping people feel that they are being listened to?

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