



Joint Committee on Human Rights

Oral evidence: [Protecting human rights in care settings](#), HC 714

Wednesday 23 February 2022

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Members present: Ms Harriet Harman (Chair); Joanna Cherry MP; Lord Dubs; Florence Eshalomi MP; Lord Henley; Baroness Ludford; Baroness Massey of Darwen; Angela Richardson MP; David Simmonds MP; Lord Singh of Wimbledon.

Questions 17 - 24

Witnesses

I: Dan Scorer, Head of Policy and Public Affairs, Royal Mencap Society; Sam Cox, Knowledge Officer (Legal and Welfare Rights), Alzheimer's Society.



Examination of witnesses

Dan Scorer and Sam Cox.

Q17 Chair: Welcome to this session of the Joint Committee on Human Rights. This is the second evidence session of our inquiry into protecting human rights in care settings: that is, the rights of residents in care. Today, our session will focus on matters connected to capacity and mental health. We all feel very grateful indeed—in particular, this was accentuated during the Covid crisis—for the work that goes on in residential care homes, but we also have to look at the rights of residents of care homes. That is what we are looking at in this inquiry.

We have previously heard evidence from families of residents who have found themselves not able to visit residents in care homes. That pertains to the human right of the right to family life. We also heard from a safeguarding expert and organisations that provide support to people in care. We have two panels of witnesses today who are giving evidence to our committee, which is half members of the House of Commons and half members of the House of Lords.

After this inquiry, we will do a report that will be published to the House of Commons. Should we feel that any changes in the law are necessary to protect the rights of residents in care homes, we will probably have a legislative opportunity. If the Government bring forward their change to the Human Rights Act, that will provide us with a legislative opportunity to bring forward new rights and put to Parliament the proposal for new rights for those in care homes, should we feel that they need to be spelt out in primary legislation. We have a report forthcoming, but also possibly a legislative opportunity in the pipeline, so we are very grateful to our two panels of witnesses this afternoon.

The first is Dan Scorer, who is head of policy and public affairs at the Royal Mencap Society, which, as people will know, is an organisation that supports people with learning disabilities, providing services, information and advice. Thank you very much for joining us, Dan, with all your expertise that you bring. Similarly, a very well-known, long-standing and important organisation is the Alzheimer's Society, and we are grateful to Sam Cox, who is responsible for legal and welfare rights at the Alzheimer's Society, which, as well as providing direct services, provides information to people affected by dementia, funds research and campaigns for change. Thank you for joining us, Sam.

I will start with the first question. We are looking at things this afternoon through the prism of the issue of human rights. Lack of access to adequate care can amount to a violation of the positive obligation that is on the state to secure the right to life under Article 2 of the European Convention on Human Rights and of the right to health under Article 12 of the International Covenant on Economic, Social and Cultural Rights.

To what extent do people with dementia or people with learning disabilities and or autism face difficulties accessing treatment, diagnosis and specialised care in a way that could be construed as impinging on



their human rights?

Dan Scorer: The first key thing is that the learning disability mortality review, which is now run by NHS England, has spelt out very clearly the huge challenges that we face in the level of discrimination that people with a learning disability experience in accessing healthcare services. The mortality review, in its most recent annual report, has shown that women with a learning disability die 27 years earlier than the general population, and men 23 years earlier; those are truly shocking figures.

The reasons behind that are complex. It comes down to the range of systematic barriers that people with a learning disability face in accessing health and care services. Barriers include the failure to make reasonable adjustments so that people do not get information in a format that they can read, appointments not being made long enough, things not being explained to them properly, and key laws like the Mental Capacity Act in many cases not being followed properly when decisions are being made about care. Pre-pandemic, we were already in an extremely serious situation, and this is an area that Mencap has been campaigning on for 15 years.

Looking at the situation now, with the vast challenge that the health service faces in recovering from the pandemic, some NHS trusts have started to set out very positive measures. Mid-Yorkshire is prioritising people with a learning disability in relation to urgent and non-urgent care, because it recognises the disproportionate impact and suffering that lengthy waits for treatment can create. We have also had some positive announcements on funding for expanding urgent dental treatment, with people with a learning disability prioritised. That is very welcome.

Again, we have seen through the pandemic further systematic barriers put in place. For us, at the moment, a huge concern is the move towards remote consultations. An issue that we have encountered repeatedly in tackling access to healthcare for people with a learning disability is diagnostic overshadowing, where a clinician mistakes clear symptoms of pain or illness as being the person's normal presentation due to their impairment when it is not. It is actually because something is seriously wrong, but the opportunity to diagnose is missed, which places the patient at significant risk. We are extremely concerned at the moment about the barriers that people with a learning disability are experiencing in getting face-to-face consultations with clinicians, where the right questions can be asked and people can get diagnosed, often with serious illnesses that need urgent treatment.

One other issue that has been of great concern to us is access to healthcare for people with a learning disability who are detained in in-patient mental health units. There has been ongoing concern throughout the pandemic that people who are detained under the Mental Health Act in those settings are not getting access to the healthcare that they need, and some have died. There have been recent investigations into this, one by the Norfolk Safeguarding Adults Board, which made a series of recommendations that NHS England have accepted. We think that a



range of further work needs to be done to make sure that people who are detained in those kinds of settings get access to healthcare.

Chair: Those figures of more than 20 years' difference in life expectancy are stark when you think that the right to life is one of the most basic human rights that the state should be protecting. Sam, could we hear your reflections on that?

Sam Cox: Diagnosis has always concerned us at the Alzheimer's Society, even before the pandemic. It was good to see that, in March 2020, they were hitting the national targets for dementia diagnosis rates, at roughly two-thirds, but that has dropped and has not yet increased back to those rates. Just as an example, in January, another 35,290 people needed to be diagnosed to hit that same two-thirds target. That means that every person who does not have a diagnosis is unable to get the services and support that they need and which are crucial to ensuring that people can continue living their lives, getting that support and even having access to some of the drugs that can help with the symptoms and with the deterioration of the condition. There needs to be a lot more funding to get those diagnosis rates back up instead of continuing with this decline.

You also asked about specialised care. In speaking to people affected by dementia, they tell us time and time again that the care they are offered, where they are offered it, is more about meeting basic essential functioning tasks such as washing and dressing. Obviously those are crucial, but well-being principle is not about looking at personalised care and what the person actually needs to live a full life and the life that they want to live, which is really important. The Care Act was meant to look at that. The well-being principle was about ensuring that care assessments looked at those personal issues, but it does not seem to be coming across in practice. It really needs to be looked at. Funding is needed in the social care system anyway, but we also need to allow the move to more personalised care, which was meant to happen.

We also see that around 200,000 with dementia do not receive any support services. That means that they are often relying on informal care or are just not receiving care at all unless there is a crisis point. Again, without getting that help and support, there is deterioration and people are just not able to live the lives that they deserve to live.

Q18 **Joanna Cherry:** Good afternoon, everybody. I am the Member of Parliament for Edinburgh South West. I want to ask about "Do not attempt cardiopulmonary resuscitation" notices. In our first session in this inquiry, we heard evidence from Helen Wildbore from the Relatives and Residents Association, who raised the concern about the inappropriate use of these notices.

Do people with dementia, learning disabilities and/or autism have specific vulnerabilities that should be taken into account in decisions about "Do not attempt cardiopulmonary resuscitation" notices, and what sort of mitigations can be put in place? Mencap raised concerns about this specifically in its written evidence to us, so I wonder whether I could start



with Dan.

Dan Scorer: Along with others, at the start of the pandemic we raised significant concerns about the emergency care guidance that NICE issued, which set out use of the clinical frailty scale in relation to establishing which disabled adults of working age would be prioritised for access to Covid treatment. We and others argued very strongly that that was completely inappropriate and that the fact that someone had care and support needs should in no way disadvantage them when it comes to decisions made about whether they would get access to treatment.

Although NICE listened, responded, withdrew and amended that guidance, what then followed, as I am sure Helen covered, was an extremely worrying period when many GPs were contacting care settings and initiating conversations about advanced decisions on people's wishes for treatment were they to go into hospital. In many cases, GPs were advising care settings that people with learning disabilities should not go into hospital because they were not going to be prioritised for treatment. That was shocking and extremely worrying.

We have been working on the issue of DNACPR for many years, since our 2007 campaign report *Death by Indifference*, because families have repeatedly flagged up to us where they have been not involved in or have been excluded from conversations about decision-making relating to DNACPRs for loved ones who did not have capacity to engage in those conversations and who, in many cases, have found those "Do not resuscitate" notices in medical files later down the line.

It was welcome that, following the issues with the NICE guidance, the then Secretary of State for Health asked the Care Quality Commission in England to undertake a review of what had happened and to make recommendations for policy and practice England-wide. The CQC's recommendations are very welcome. We support them on a clear national approach to advanced decision-making and improving staff training on legislation such as the Mental Capacity Act. A working group has now been established by the Department of Health to look at this.

Our worry is that, following the pandemic, many people with a learning disability could have "Do not resuscitate" notices on their medical files that have not been noticed, so it is very important that NHS England has prioritised a review of that. This is an issue of ongoing concern, but we are somewhat reassured that the Care Quality Commission, the Department of Health and NHS England are taking this seriously and seeking a co-ordinated national approach.

Joanna Cherry: You started your answer by explaining that some decision-making seemed to indicate that people with a disability would be deprioritised for Covid treatment. As well as a human rights issue, is there not an issue of disability discrimination there, because it is a protected characteristic? It seems quite shocking that that could happen.



Dan Scorer: Yes, absolutely. It was unacceptable. As soon as we got in contact with NICE, it recognised how serious its error was in trying to apply the clinical frailty scale to disabled adults of working age—the scale is used for making decisions about care for older people—and in making negative inferences on the basis that people had care and support needs to go about their everyday lives. That was absolutely unacceptable, as you say, and direct discrimination, and it was very quickly revoked and amended.

Joanna Cherry: Would it have been had it not been for your intervention?

Dan Scorer: I do not know that it would. There was an outcry from us and many others who were absolutely shocked by what had been issued and who could immediately see how dangerous it was when we were already very concerned about what the experiences of people with a learning disability going into hospital for Covid treatment were going to be, when, in many cases, people may not have had staff or loved ones able to go with them. People were not going to have advocates and supporters with them when going into hospital, so whether reasonable adjustments were made for them, whether they were properly supported and whether they could communicate effectively were all of huge concern for us.

Then this guidance came out, which was absolutely shocking in that it directly undermined the ability of disabled people to get treatment for Covid and was on a basis that was absolutely unacceptable. Our concern was that, even after it was revoked, it was still there circulating, and many clinicians may have seen the old version and not the new version. That is why the CQC's review to look at what had happened was so important, because so many care settings up and down the country were being contacted by GPs talking to them about initiating conversations with residents and families about what their treatment wishes would be were they to go into hospital for Covid treatment and, indeed, whether they should be going into hospital. That was the most worrying aspect: almost encouraging people to stay in care settings and not seek treatment, which we absolutely did not want to see happen.

Joanna Cherry: Sam, could I turn to you? I will remind you that the question was whether there are specific vulnerabilities for people with dementia that should be taken into account in decisions about these notices, and about the mitigations that can be put in place.

Sam Cox: A bit like Mencap in a way, we have been concerned about this issue for quite a number of years. Specifically on dementia and mitigations, one of the worrying things is the assumptions that are made, with blanket policies coming in and decisions being based on a diagnosis rather than the person. For us, one of the most important things in this area is ensuring that any decision is an individual decision and is based on that person and their needs and wants and that it is not made solely on the label of dementia.



It is quite sad that I still have to stress that, because again during the pandemic we saw that people had not even had a conversation with the person and that the person was still given a DNACPR order, which is completely unacceptable. People actually received them in the post without any prior warning. That has to stop. That cannot happen again. We have spoken quite a lot about this internally. We would like to see staff and clinical awareness, and awareness among the general public, as to what they are and the fact that, if you have one, you can challenge it and get a second opinion.

I know there is no standard form, but the red forms, as they are often referred to, are very much the same, really, or very similar. Maybe there should be something on that form to say where people can go to get more advice and support, because there is not at the moment. For some people, when they find that form among their relative's possessions when they come out of hospital, that is the first they know about it. Having something on that form would be really helpful.

Q19 Angela Richardson: Hello, panel. I am the Conservative Member of Parliament for Guildford. My question is on the use of restrictive practices. Restrictive practices can impact on the right, under Article 3 of the ECHR, to be protected against torture and inhuman and degrading treatment, and the right, under Article 5 of the ECHR, to liberty and security. Do you believe that there are sufficient safeguards in place to prevent the misuse of restrictive practices on people with dementia or learning disabilities and/or autism in all care settings?

Sam Cox: I do not want to be blunt about this and just say no. I will try to explain my answers. I know that the next panel will be speaking about DoLS, but I do not think you can speak about Article 5 without mentioning the deprivation of liberty safeguards. We all know that it has been recognised that this scheme is not fit for purpose. It was said in the House of Lords Select Committee review of the Mental Capacity Act back in 2015. As an organisation, we welcomed the review of the deprivation of liberty safeguards that followed.

As we know, there have been a lot of problems. The latest figures show that currently almost 120,000 people are awaiting their review and so do not have the safeguards. Of those, 46,000 have been waiting for over a year for that assessment. Those are the most vulnerable people in our society, whose freedom is being restricted and for whom there are no human rights safeguards in place to protect them at the moment. It is people who cannot stand up for themselves in a lot of cases, and that needs to be looked at.

I understand that the liberty protection safeguards, the new scheme, will come in in due course, but that has been delayed time and time again. Also, as an organisation, we cannot really say at the moment whether we feel that it will be an adequate safeguard or will work in practice, because we do not have the code of practice or the regulations. It would be reassuring if there could be a push to ensure that it is reviewed properly and looked at after its introduction in order to ensure that it is an



effective safeguard, that is doing the job that it is meant to do, and that it is involving people affected by dementia and other conditions under those safeguards to make sure that they are working.

Also on restrictive practices, and moving slightly away from DoLS, it is also about ensuring that staff have the right training and support. That is crucial, and we are seeing that there are times when with dementia in particular are not given the personalised care that they need from appropriately trained individuals. They might actually need more restrictions placed on them.

I will give you a very simple case example that I dealt with a few years ago. We became aware of a gentleman in a care home who got aggressive at certain points of the day. One of his night-time carers was really surprised when they were discussing the use of sedatives and other things to calm him down because he would lash out. She said, "It's not like him. Why is that happening?" That member of staff had been on a dementia awareness course and was tier-2 trained, and she looked into it. She realised that he was not able to verbalise his feelings. He was lashing out because of certain TV programmes about the war that came on, and it would bring back those memories for him. Simply ensuring that he was not around that meant that he did not lash out, so there was no need to look at chemical restraints and other things that were being looked at.

That is a very simple example that shows that, by having the right thinking and the right level of training for staff, you can take away some of the restrictions that are sometimes used and thought about. As I said, as well as having these rights and safeguards, looking at staff training and that level of support for staff to enable them to look at these cases is really helpful.

Angela Richardson: That is a really helpful answer.

Dan Scorer: I want to comment on the submission that we and the Challenging Behaviour Foundation made on safeguards relating to people with a learning disability and autistic people in in-patient mental health units where there are certainly not sufficient safeguards. Although it is mandatory for NHS organisations or trusts and independent hospitals delivering NHS-funded care to submit data on the use of force and restrictive practices to the NHS Digital dataset that monitors this, it does not cover children and adult social care services.

Also, even within the NHS data collection, the majority of independent care sector hospitals and a minority of NHS organisations are not submitting data even though it is supposed to be mandatory, so the picture that we have on the use of restrictive practices is far from complete. The CQC was very clear on this in its *Out of Sight* report, which it released in 2020, on the use of restrictive practices. It recommended that there should be a national reporting mechanism on the use of restrictive interventions in children's—



Chair: Sorry, Dan. Can I just interrupt you? I wonder whether it would be helpful for you to say what restrictive practices are.

Dan Scorer: Of course. We are talking here about the use of chemical restraints: the use of anti-psychotic medications; physical restraint—holding people down; seclusion—people actually being locked in solitary confinement-type conditions; and segregation, which is keeping people away from others on their own area of a ward. The CQC was calling for a national reporting mechanism to be developed on the use of the restrictive interventions in children’s and adult social care services, so we have similar data to that that is partially collected by NHS Digital, and regulatory changes so that providers have to notify CQC when restrictive practices are used in children’s and adult care services. That would certainly be a positive step.

In relation to the position of people with a learning disability and autistic people in in-patient mental health units, we have to recognise that restrictive practices are often used because those settings are fundamentally unsuitable and those people should not be there. It is welcome that the Government are moving forward later this year with reform of the Mental Health Act, which will remove autism and learning disability as grounds for sectioning under the civil part of the Act, certainly for long-term detention beyond 28 days. It is important for the Government to recognise that unless autistic people and people with a learning disability actually have a diagnosed mental health problem, they should not be in these units. In many cases, the environment there is totally unsuited for them and puts people in a position where they are trapped, where behaviours escalate and they cannot get the support they need, so we see an escalation of restrictive practices.

Ultimately, we want to see the Transforming Care and Building the Right Support programmes, which NHS England and the Department of Health are leading on to develop community options, addressing, at a system level, inappropriate treatment whereby people are subjected to restrictive practices.

Q20 Lord Dubs: I am a Labour Member of the House of Lords. The right to respect for private and family life is protected, as you know, by Article 8 of the European Convention on Human Rights. The exercise of this right includes considerations about the ability of an individual to choose where, how and with whom to live. To what extent are people with dementia or with learning disabilities and/or autism able to exercise this right while in care?

Sam Cox: We see Article 8 as a right breached and violated time and time again for people with dementia. I always find in the cases that I have worked on or worked with, and when speaking to some staff members when we are looking at our cases in this area, that in practice it is a very hard right to enforce. This is mainly because, unlike the other rights that we have mentioned today, Article 8 is not an absolute right. It can be limited time and time again. We saw that in the care homes during the pandemic; it was limited because of the health and morals of



others and because of national security and so on. But we see it being limited on a day-to-day basis, simply because of a lack of resources.

Article 8 is a very wide right. It is not just about seeing family and having the right to your home and private life. It is also about your dignity, autonomy and rights of control. In some ways, it is those everyday things that we all take for granted until they are taken away from us. When it comes to people with dementia, we often see Article 8 not being able to be fulfilled because there is a lack of choice and control. When we talk about community care and rights in the community, for example, often the choice is quite simply that you will have care at home for as long as possible and then you will move into a care home. That tends to be the kind of choice that is out there, which is not a real choice. It is not giving somebody that full autonomy.

We saw those restrictions in care homes with people not having the right to be visited. Where somebody's care is being funded by the state or they need specialist mental health provision in the units, they are often moved quite far away from family and the family is unable to visit. Again, we might try mentioning Article 8 in challenging that, but it does not really get us anywhere, because there are no real options available for people with dementia. That shows, again, that we need more resources so there is proper provision for people so that they can have these choices and be near their loved ones and be able to see family.

Something more is needed in the law, because we have seen that the current legislation is not sufficient. Something extra needs to happen to ensure that this right is fulfilled for people with dementia.

Dan Scorer: Following on from Sam's point about people in in-patient settings, there are over 2,000 autistic people and people with a learning disability in in-patient settings. Their average length of stay is more than five years, when those settings should be used for short-term periods of assessment and treatment, so there are profound implications for people's right to family life, given that many are sent far away from home and, as Sam was saying, it can be incredibly challenging for the family to visit.

Also, there are significant delays in discharging people from those settings and back into their communities to be near their families and to family homes. The two reasons given for that in the NHS data are a lack of housing and a lack of the right care and support options in the community, so there are serious system-wide issues with people not being able to exercise choice and to leave those settings in a timely way.

Also, just reflecting on the position of people in the community and having a choice about how to live, we have a network of 400 independent local groups. From our regular conversations with them, it is very clear that, post pandemic, there are major issues with things like day centre services getting back up and running to full capacity. There are serious staff shortages, which have been exacerbated for example by the recent confusion about the policy of vaccine as a condition of deployment of staff



in care settings, with many staff having left the sector. Also, we are seeing local authorities, hard-pressed budget-wise, carrying out a number of consultations on increases in charges, cuts to personal budgets and service reconfigurations, all of which are having a very serious effect on people's choice about how to live their lives and on the support that family members who are caring full time for loved ones have.

Q21 Lord Singh of Wimbledon: Good afternoon. I am a Cross-Bench Member of the House of Lords. Are health and social care staff adequately trained to take into account relevant human rights considerations for people with dementia, learning disabilities and/or autism? Is there adequate monitoring of skills and training? If not, how could this be achieved?

Dan Scorer: To answer your question directly, no, training is not consistently adequate. In terms of opportunities, we have been very pleased to be part of a pilot that Health Education England has run over the past couple of years on new training on learning disability and autism, called the Oliver McGowan mandatory training in learning disability and autism. Oliver was a young autistic man who lost his life in tragic circumstances, and his mother, Paula McGowan, has been a tireless campaigner, calling for training for all health and care professionals on learning disability and autism. That was also a recommendation by the learning disability mortality review in its 2018 annual report, which the Government accepted. The pilot that we have been involved with over the last year has been part of efforts to trial that training, which the Government have committed to rolling out to all 3.7 million health and care staff next year.

An independent evaluation of that training pilot is due to be finished next month. The Department of Health, NHS England and Health Education England will have important decisions to make about the rollout of that training for health and care professionals. The training has the potential to be transformational in the impacts that it can have on professionals' awareness of the rights of people with a learning disability and of autistic people and how to make changes to services to respect their human rights and make services accessible to them.

Lord Singh of Wimbledon: It is not easy, but it is good to know that there are attempts to address the problem.

Sam Cox: As I mentioned earlier, correct training in dementia can be really beneficial to lessening the use of restrictive practices. We are calling for it as an organisation, and we believe that all social care staff should have tier 2 training in the dementia training standards framework. It can obviously help with human rights issues too.

A lot more needs to be done on awareness of the Mental Capacity Act, the Mental Health Act and DoLS, particularly the interface between the two Acts. The review of the deprivation of liberty safeguards, the liberty protection safeguards—as they will be—and the Mental Health Act review



have not come to terms with or dealt with that interface between the two Acts. The CQC has said that staff need to be more aware of that interface and how best to deal with the issues caused, and to know which is the correct law for the correct person at the time when they need to be under them. A lot more needs to be done on those things.

In terms of the workforce generally, the APPG on dementia is currently undertaking an inquiry on this very subject of skills and training and how that needs to be appropriate. We would encourage this committee to engage with that inquiry and its findings, too.

Lord Singh of Wimbledon: Thank you so much. That is very helpful.

Q22 **Florence Eshalomi:** Thank you to our guests this afternoon. I am a Labour Co-op MP representing Vauxhall. Following on from the earlier questions, we briefly touched on one of the issues, which is about the complaints system that families and their carers have to navigate. How can the complaints mechanism be improved to allow the Care Quality Commission to be more effective in its role in protecting care users from human rights breaches?

Dan Scorer: The experience that many families report to us, when they have very serious concerns about the treatment of their loved ones in care settings and are making complaints to the CQC, is that they are told that it cannot get involved in individual cases, but, of course, it regulates the overall quality of the service in terms of it being safe and well led and staff being caring. The important thing here is that there are very strong links with local safeguarding teams so that, when concerns are raised about an individual, they are urgently escalated, investigated and addressed and that the wider quality of that service is also looked into.

There are serious issues that need to be addressed, such as when a service is rated as inadequate, which is increasingly happening as the CQC has taken a much more assertive role in investigating many of the in-patient units that I have talked about previously, many of which have serious problems that have been identified. The CQC needs to use its powers to stop new admissions into those units. If a unit is rated inadequate, commissioners should not be able to admit people to those units, which happens.

The other thing is the CQC having much more detailed and regular oversight of services where very serious concerns have been expressed, where they are inadequate and where they have a six-month period of time to implement an improvement plan. There needs to be much more regular oversight of that process and communication with families, who will be incredibly worried about the quality of that service and whether their loved ones are safe. Families need to be updated about whether that service is heading in the right direction or whether there are ongoing serious problems that are being picked up.

Q23 **Chair:** The protection of human rights is very much dependent on the ability of people to enforce their rights. Without enforcement, rights will



often not be a reality. Do you feel, in view of the evidence that there is financial precariousness in the sector, that that might have a chilling effect on the Care Quality Commission in deciding that places that it regulates do not have suitable quality of care and protection of people's rights? Does the fact that the sector is so financially precarious work as a chilling effect on insisting on high standards of quality of care by the regulators?

Dan Scorer: Undoubtedly, there is a very strong risk of that being the case. We have been involved in a number of cases where services have been closed at very short notice because of major concerns, and there has then been a scramble to find places for people in other settings. We have looked at issues like the placement of people with a learning disability in in-patient units, a serious lack of community provision and a lack of progress over recent years in developing that, and yes, that undoubtedly creates huge stress from the point of view that, if those settings are closed, there are major concerns about the alternative provision for people. I am sure that weighs very heavily on the minds of everyone involved.

Sam Cox: Touching on what Dan said at the beginning, we have the same issue; people will attempt to contact the Care Quality Commission and literally be dismissed and told, "We don't deal with individual complaints", which can be very off-putting for families who might not know of any other recourse for getting their complaints dealt with or what to do. We feel that more needs to be put in place and that maybe the CQC should consider individual complaints, or at least be able to offer more advice and information to families.

We hear a lot from families about how they are hesitant to complain, because initially they have to take their complaint to the actual provider. They then fear that that will affect their loved one and that somehow their complaint will be taken out on their loved one. I am afraid to say that we see cases where, following a complaint, people are told that the provider can no longer provide care for their loved one, so they are actually asked to move, or where relatives who have put in a complaint have been banned from visiting because of the complaint and what has happened. There is this fear, and given some of the cases that we are seeing, it is justified that families have that fear.

So it is felt that there should be something a little more independent, rather than having to take something to the actual provider. Somebody away from that could look at these complaints, so that these things could be looked at.

In a survey of carers undertaken by TIDE, 75% of respondents said that nobody from their council told them how they could complain about services that the person they care for receives. Again, there is a lack of awareness. Often, when somebody is receiving care or is moved into a care home, a lot has happened to get to that point, so people are often exhausted and unable to deal with what has happened, never mind then thinking, "Okay, we've gone through all this. We're now getting care that



we're not happy with. What do we do about this?" There needs to be a lot more in place to help and support people to know how to get their rights achieved and how to get these things looked at when they come up, and as quickly as possible.

Chair: Basically, you are saying that it is not just about the potential impact on the regulator and the worry about closing a home and what will happen to the residents if an inadequate or unsafe home is closed, but the chilling effect on relatives fearing that there might be retribution or that the resident might be excluded from the care home and then go out of the frying pan into the fire. The difficulty of enforcing rights is very much in that context. You have both made that very clear indeed.

Q24 **Baroness Massey of Darwen:** Good afternoon and welcome. I am a Labour peer in the House of Lords. My question is about community support and its relevance to choice and rights. Sam and Dan have both referred to communities, and I am aware that Mencap, the Alzheimer's Society and others are concerned about community involvement. Dan mentioned that Mencap has 400 local groups. What can be done to improve community support for people with dementia or learning difficulties and/or autism?

Dan Scorer: In relation to the group of people I mentioned earlier, people with a learning disability and autistic people in in-patient units, community support is absolutely vital and has been one of the things that has held back the programme of work by NHS England, the Department of Health and others over recent years, because the community support is simply not in place. On the positive side, the Department of Health and Social Care will release, probably by the end of March, a new cross-government action plan on building the right support. The focus on community provision is going to be a key aspect in that.

Over recent years, there has been more focus on this, with the Government making a community discharge fund available to support the development of community services for people with a learning disability, autistic people coming out of in-patient units, and more capital grants from NHS England to develop housing options. The focus has been on closing beds in units and not adequately on developing those community services. For us now, the Health and Care Bill and the placing of integrated care systems on a statutory footing is a key opportunity to address this, because the pooling of budgets and the integration of health and social care services just has not happened.

One of the things we have been calling for during the passage of the Bill is for the Government to honour their commitment that integrated care boards will have a lead executive for autism and learning disability who will, in the area, champion the development of community services and meet the commitment to develop that support for autistic people and people with a learning disability so that they can leave in-patient settings and resettle in the community and that a new generation of people does not go into those units. If we have that leadership, the pooling of budgets



and that focus on this agenda, we have a key opportunity now for the benefits of integrated care systems to be realised.

Baroness Massey of Darwen: Who sets up local groups?

Dan Scorer: Many of our local groups, which are independent organisations, were set up by family members. Many are 50 or 60 years old. They range from small volunteer-level organisations through to large regional organisations with multi-million-pound turnovers that deliver services themselves.

Sam Cox: I have mentioned a few times community support, community care and people with dementia. Again, just to reiterate, one of the biggest concerns for us is ensuring that the person is at the centre of that. So, for us, if community support is to be looked at at any point, it needs to be about what the person with dementia themselves needs and wants in order to live a full life, because every person is different. We recognise that and the Care Act recognised that, and we need that to come to fruition. We need to ensure that that community support is about ensuring that the person can live the life they want.

Since the pandemic, polling that we have done has indicated that more people are less inclined now to look at residential care or to look at it for themselves or their loved ones, which means that domiciliary care and care in the community in people's own homes are becoming more and more popular. Again, it needs to be a choice that people can make and have and that the support is there to enable people to live at home for as long as they want to and for that to be a real option for people. That is coming out again and again for people with dementia, and it is really important to them.

Baroness Massey of Darwen: Are there ways in which community support could be improved? If so, how?

Sam Cox: To start with, it needs to be looked at properly and reviewed, and that review needs to start by asking people with dementia what they want. Again, at the moment, we are hearing from people that the community support they are offered is everyday basic, essential care, so it is just about washing, dressing and eating, and not about accessing their community. It is not about saying, "Okay, you like to go for a game of tennis. Let's make sure you can still go and have your game of tennis". It needs to be more than that. Well-being and mental health are a lot more than just being able to eat, get up, get washed and get dressed every day. They are a lot more important.

Again, we are talking about rights. Article 8 is about having the autonomy, control and dignity to be able to live your everyday life. Community support needs to go back to that. It needs to look at what people individually want out of their life and what it means to them to live a good life.

Chair: Thank you very much indeed. That is the final question for this



panel. I am very grateful indeed to you both for the written evidence that you have submitted to us from your organisations and for the evidence that you have given us today.