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Health and Sport Committee

Tuesday 14 November 2017

Session 5

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 14 November 2017

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HEALTH AND SPORT COMMITTEE

26th Meeting 2017, Session 5

CONVENER

*Neil Findlay (Lothian) (Lab)

DEPUTY CONVENER

*Clare Haughey (Rutherglen) (SNP)

COMMITTEE MEMBERS

*Tom Arthur (Renfrewshire South) (SNP)
*Miles Briggs (Lothian) (Con)
*Alex Cole-Hamilton (Edinburgh Western) (LD)
*Jenny Gilruth (Mid Fife and Glenrothes) (SNP)
*Alison Johnstone (Lothian) (Green)
*Ivan McKee (Glasgow Provan) (SNP)
*Colin Smyth (South Scotland) (Lab)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Rachel Le Noan (Down’s Syndrome Scotland)
Carolyn Lochhead (Scottish Association for Mental Health)
Clare Ogden (Action for ME)
Derek Young (Age Scotland)

CLERK TO THE COMMITTEE

David Cullum

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 14 November 2017

[The Convener opened the meeting at 10:01]

NHS Governance

The Convener (Neil Findlay): Good morning everyone, and welcome to the 26th meeting in 2017 of the Health and Sport Committee. I ask everyone in the room to ensure that their mobile phones are switched to silent. It is acceptable to use mobile phones for social media, but not to record or photograph proceedings.

Agenda item 1 is our first evidence session on clinical governance in the national health service. I welcome Rachel Le Noan, who is the policy officer for Down’s Syndrome Scotland; Clare Ogden, who is the head of communications and policy for Action for ME; Carolyn Lochhead, who is the public affairs manager for the Scottish Association for Mental Health; and Derek Young, who is the senior policy officer for Age Scotland. We have received apologies from Tanith Muller, who is the campaigns manager for Parkinson’s UK in Scotland.

We have approximately one hour for our session this morning. We will move directly to questions. Colin Smyth will begin.

Colin Smyth (South Scotland) (Lab): Good morning. I thank the panel for coming to give evidence.

I will start with a question about implementation of standards and variations in care. A plethora of clinical standards and guidelines exist, but some of the written evidence that the committee has received raised concerns about how well those standards and guidelines have been implemented. In your experience, do health professionals demonstrate adequate knowledge of the relevant standards? Do patients generally receive the treatment that they should, as set out in the guidelines and standards?

Carolyn Lochhead (Scottish Association for Mental Health): We find that the standards and guidelines on mental health, where they exist, are generally good, but there is no widespread or consistent understanding of them. A few years ago, we did some work with general practitioners, in which we asked them particularly about the Scottish intercollegiate guidelines network guidance on non-pharmaceutical treatment for depression. About half of GPs were not aware, or were not sure whether they were aware, of the guidance.

That is reflected in the experience of people we work with, of whom we surveyed more than 300. They talked about a sense of not feeling clear about what they are entitled to, or the systems that are supposed to be in place to protect them, and of often waiting a long time to access treatment. We feel that there is no widespread awareness or understanding, but that the guidance itself is good.

Clare Ogden (Action for ME): I would echo Carolyn Lochhead. The “Scottish Good Practice Statement on ME-CFS” was published in 2010: when GPs were surveyed four years later, two thirds said that they were not aware of that statement. Those who used it thought that it was good, but there were still GPs who were not even aware of it four years after it was published. That is reflected in the patient experience, too—many patients say that their GP does not understand ME and gives them bad advice that does not help.

Rachel Le Noan (Down’s Syndrome Scotland): I will base my evidence on the report that we published earlier this year. Four hundred of our members, including 200 with Down’s syndrome, replied to a survey that we conducted on healthcare. The issue for us relates to pregnancy screening standards—I raised that point in our submission. Those guidelines need to be, and are currently being, updated. The fact is that they are not being met all the time. In some cases, appalling care is provided to expectant or new parents welcoming a baby with Down’s syndrome. There is a difference between what is on paper and what is implemented on the ground. I agree with the other panel members that although standards exist, there are serious issues with their application that need to be considered.

Derek Young (Age Scotland): I would echo what the other witnesses have said. We are now quite good at writing standards, through drawing upon previous evidence and iterations of the same standards, in many instances.

Age Scotland had an opportunity to be involved in the consultation on the new standards of care for older people in hospital, which were published in July 2015, and in the new overarching national health and care standards, which were published this year. A couple of years later, the standards of care for older people in hospital are still, in many instances, not forming the basis for inspections of older people’s hospital services. We cannot point to direct evidence of health professionals understanding the new hospital standards, but if the standards are not being used as the basis for inspections, it would be reasonable to assume that they are not a central part of decision making or of the culture that exists within hospitals on those standards and how they are implemented.

Through our national telephone helpline, we receive calls from older people and their families about instances in which they feel that, first, they have not had the sort of care that they had hoped for and, secondly, they do not know what the standards are and how to resolve grievances or raise concerns about how their care could be improved.

Colin Smyth: Parkinson's UK's submission highlights that a person with Parkinson's has to have their medicine on time, but it is constantly running a campaign to raise awareness among professionals that that needs to happen: it is a constant battle. You guys can run campaigns to raise awareness, but what needs to happen in the NHS to make sure that standards are properly implemented?

Rachel Le Noan: We have been invited to join the group that is currently reviewing the pregnancy screening standards. One of the issues that I am struggling to come to terms with is that although the standards are issued by Healthcare Improvement Scotland, as far as I understand the situation, Healthcare Improvement Scotland does not have any power to monitor or implement the standards. It is up to each health board to decide how it does that. There is an issue of accountability; who is checking what is happening in each health board?

The Convener: With standards covering so many different conditions, does anyone know how many different standards publications there are?

Carolyn Lochhead: I could not give you a figure. In mental health, there are the National Institute for Health and Care Excellence's and SIGN's guidelines. There are certainly more mental health standards in NICE than there are in SIGN. There are not so many that it would be unreasonable to expect people to have a sense of them, especially because it would be quite unlikely—in mental health specifically—that one would need to know about all of them because many are quite condition specific. My sense is that there is not an overwhelming number of standards.

The Convener: Is there commonality across the piece in some of the basic standards that should apply?

Carolyn Lochhead: That is a good question. I would say broadly yes—I have certainly never come across anything in a standard that I felt contradicted something elsewhere.

Derek Young: There are several sets of standards that we know of. I could not give a definitive figure, but we would certainly be prepared to follow up in writing how many standards we are aware of, and which ones older people routinely confront in hospital settings. As Carolyn Lochhead mentioned, there are condition-specific standards—those relating to dementia are obvious. There are also standards about processes that are not condition specific, such as the food, fluid and nutritional standards.

In response to Colin Smyth's question about what needs to happen within the NHS, Age Scotland's written submission references examples where things have gone very badly wrong. Both examples—Mid Staffordshire NHS Foundation Trust and Winterbourne View hospital—are from England, but they remain pertinent. Following the Mid Staffordshire scandal, the Francis report outlined several hundred recommendations. In broad terms, the critical factor in ensuring that effective change and a culture of quality, supported by leadership, were established was for NHS trusts to focus on quality of care and a patient-centred approach, rather than on processes and finance. Written standards on their own, unless they are imbued with differences of approach and the differences in behaviour and decisions that are made every day, really do not have the value that we would be looking for.

Clare Ogden: In answer to the convener's question on the number of standards, there is a single NICE guideline for ME as well as the "Scottish Good Practice Statement on ME-CFS" that I mentioned. We find that lots of recommendations that are made do not then become standards—in 2002 there was a short-life working group on ME, in 2007 cross-party group reports identified areas for action, and in 2010 there was a healthcare needs assessment. Lots of elements from all of those pieces of work have still not been put into practice.

Colin Smyth: Your organisations all have a wealth of knowledge in your areas and will be involved in publication of guidelines. Are you involved in any work on implementation of the guidelines? Does the NHS come to you, checking whether things have been properly implemented, or do you just have to flag up problems where you see them, as Derek Young has just suggested?

Clare Ogden: There has not been any concerted effort to make sure that the professionals who need the guidelines work with them. Of the GPs in our survey who were aware of the "Scottish Good Practice Statement on ME-CFS", nearly half did not use it. They know that it is there, but do not use it, so we need to find out why that is.

Brian Whittle (South Scotland) (Con): Good morning. I am interested in the role of Healthcare Improvement Scotland. It seems to be the main regulatory body within the NHS. With that in mind, is it sufficiently independent of the NHS and, indeed, of the Scottish Government? Does it have adequate powers to ensure that the necessary improvements are made and that guidelines are adhered to?

Rachel Le Noan: I can talk only about the issue that I mentioned: I have limited knowledge. As far as I understand it, Healthcare Improvement Scotland will publish, and is working on, pregnancy-screening standards, but it cannot—or is not being asked to—do anything about monitoring and implementation. I find that quite troubling.

Derek Young: In many public service contexts, there is a difficult balance to be struck in terms of how independent or connected you would like your scrutiny body to be. There is a parallel between Healthcare Improvement Scotland and the Care Inspectorate. Due to health and social care integration, those organisations are working together quite closely. In recent times, the Care Inspectorate, for example, has decided to move from being an out-and-out scrutiny body to being one that is also focused equally, if not more, on driving and supporting improvement. To some extent, that trend is also emerging within Healthcare Improvement Scotland.

On Age Scotland's direct experience of Healthcare Improvement Scotland, I mentioned the standards of care for older people in hospital. We were pleased to be part of the project team that helped to put that together. I think that the only other third sector body that was involved was Alzheimer Scotland—Action on Dementia. Most of the other people in the room were from within the NHS—senior doctors and nurses or inspectors.

10:15

We did not have criticisms of the process. We felt that there was an opportunity—certainly, the fact that we were in the room give us an advantage, because not every organisation had that opportunity—to bring some outside expertise to the writing of the standards. However, we are not involved in inspections, which are the main route through which HIS sees the extent to which the standards are being implemented, and can advise territorial health boards accordingly.

Organisations including the Scottish Health Council and the patient advice and support service have more detailed information about how complaints are processed and recommendations are taken forward. We have not found the independence issue to be a problem. We simply want to ensure that the recommendations that are made are followed up on.

Carolyn Lochhead: That is fair. The situation in mental health is slightly different in that both the Mental Welfare Commission for Scotland and the Care Inspectorate inspect many services, including many of SAMH's. I am probably slightly more familiar with the reports from the Mental Welfare Commission, which we find to be robust and well researched.

I do not have a sense of there being a problem with the independence of those bodies. There are times when views have been expressed about particular processes. For example, there has been a recent change to how reviews of suicides that happen while the person is in contact with mental health services are reported, with less information now being sent from the health board to Health Improvement Scotland. We are looking to explore the issue and would like to understand it more. There are areas where we want to ensure that the process is transparent and robust, but I would not highlight a particular concern about independence.

Brian Whittle: Is the issue less to do with independence and more to do with enforcement and implementation of guidelines? In that respect, does HIS have the power to enforce the guidelines or do we need a more independent regulatory body? You said that the guidelines are robust, but they are not being implemented, so I am trying to tease out why that is.

The Convener: Who should be responsible for implementation? Currently, that responsibility sits at health board level. Is that adequate?

Carolyn Lochhead: The responsibility absolutely sits at health board level, but there is also a role for the professional colleges in upholding standards. I have to say that I am not sure about Health Improvement Scotland's powers to enforce a clinical standard. It is worth exploring the consequences if a clinical standard is not met. I do not know that I could be particularly clear about that.

Derek Young: Age Scotland does not have an official organisational view on that, but we are willing to reflect on the issue and to submit further evidence to the committee, if that would be helpful.

The Convener: Okay.

Alison Johnstone (Lothian) (Green): Some of the most concerning aspects in the submission from Down's Syndrome Scotland were about the fact that there are not even any standards yet. The submission outlines the experience of a parent who was presented with a developmental questionnaire when they took their child for a vaccination appointment and constantly had to say that their child had not yet reached certain stages yet. There do not seem to be any standards or regulation around such things. Such examples touch on issues of people being treated with dignity and respect. Do we have to look more closely at that issue?

Rachel Le Noan: Yes. We think that that is a massive issue that is currently not acknowledged or addressed. Issues around the lack of care, support and dignity and respect often come down to poor communication and the use of language and terminology by professionals. For example, if the health visitor refers to "a Down's baby", that can be quite upsetting for new parents. When somebody is taking their child in for surgery, they are, obviously, anxious about what is happening to their child and they should not also have to worry about having to challenge staff who refer to their son or daughter as "a Down's child".

We believe that something should be done around the use of language and terminology. Words have power and not all staff are using the right language when they deal with patients. There is a critical issue around the lack of dignity and respect. The situation starts early on, when parents go through the screening process, and it goes all the way through. The issue is hugely important and should be considered.

Clare Ogden: People with ME face similar issues about being treated with dignity and respect. As we outlined in our submission, only one in four feels that their healthcare professionals treated them with respect. Although there are issues around the understanding of ME and the fact that GPs perhaps do not feel sufficiently equipped to manage the condition appropriately, it is not acceptable to say to someone that you do not believe that they are ill, regardless of what the condition might be.

Carolyn Lochhead: When we surveyed people for our submission, the majority said that they felt that staff were courteous and sensitive and most people said that they felt valued as an individual, so there are some positives. People talked about having good experiences with staff, and it is always important to acknowledge that.

However, 40 per cent felt that they had been treated disrespectfully at some point. The comments in the survey—which bear out what we know from talking to people more widely—show that that is particularly the case when people have to push to get treatment or a referral. Some people spoke about feeling that they had been laughed at when they asked for psychological therapy and said that comments were made about the length of time that they were likely to have to wait for that. We hear frequently that, when there have been instances of self-harm or attempted suicide, people are made to feel that they are wasting staff time, that the issue is not a serious one or that they are just being silly. There is an issue of not only language but attitude and understanding what the issues are.

It is important to highlight the fact that people report good experiences with staff who are respectable and are absolutely trying to do their best, but there is a particular problem in relation to self-harm and attempted suicide.

Derek Young: There are two aspects to Alison Johnstone's question. We do not have specific examples that we can point to that demonstrate a lack of standards, which is one of the points that was referred to. However, the issue of dignity and respect is a major one that we have been trying to highlight for the past couple of years—it certainly appears in our written submission. The evidence that we get from our helpline is that people who have experienced NHS care say that being treated with dignity and respect is as important as the quality of care that they receive. However, there is also a different dynamic at play with regard to those questions, because people are not as qualified as medical professionals to understand the nature of their condition, the prognosis, the kind of treatments that are available and the risk factors that are involved. With regard to those elements, they are reliant on the advice that they get from health professionals. They are much more in charge, as it were, of their understanding of how they have been made to feel by their healthcare experience, so they should be treated as experts in that capacity.

As I mentioned, there have been recent changes to the standards, and dignity and respect now feature specifically in the new hospital standards from 2015. However, they do not yet form the basis of enough inspections. It is certainly true that that is a step change for professionals to deal with during an inspection process, because previous standards have been much more functional in nature and have been much more concerned with specific aspects of the healthcare process—they have talked about timings around people being offered a comprehensive geriatric assessment, the start of rehabilitation planning or discharge planning and so on. By the nature of the issue, it is harder to base an inspection on how people feel that they have been treated rather than it is to base it on the bits and pieces of how the system works. Staff will have to go through a process of change to understand how to do that.

In our written evidence, we recommend the Nolan senses framework, which was developed by Professor Mike Nolan at the University of Sheffield, who is a long-standing, experienced professor of gerontological nursing. It is a useful toolkit. We would like to see better understanding and knowledge of it in health systems and we are willing to try to promote it. If there was better understanding of it, that would lead to the culture change that witnesses referred to—changes in attitudes and decision making by staff in the NHS, rather than staff relying on standards without fully understanding the impact on their day-to-day work.

Alison Johnstone: It seems that there are standards that need to be introduced when it comes to language, behaviour and how we treat people who have conditions that we perhaps do not yet fully understand because we do not have the research background. Do you have any concerns about barriers in the complaints process? Is there anything that makes it particularly hard for people to access? Are people sometimes simply put off complaining because their initial experience is so negative?

Clare Ogden: Yes, I think that that is the case. A lot of people are struggling to cope with their condition, and having to complain is a step too far. The symptoms of ME are quite debilitating. They include cognitive difficulties and physical limitations. If somebody has only a limited amount of energy, using it on a complaint might not be the thing that they most need to do for themselves or their family. There are barriers.

Alison Johnstone: There almost needs to be somebody to take the process forward for them.

Clare Ogden: Yes, absolutely. That is particularly the case for people who are severely affected, which is one person in four with ME. They can be housebound or bedbound. Sometimes, they cannot even be touched by a loved one. Those people are desperately in need of advocacy to access the services to which they are entitled.

Carolyn Lochhead: When we did our survey, almost 80 per cent of people did not know about the systems that were in place to detect and deal with unacceptable care. There is a barrier of people not knowing that there is any kind of system for making complaints. We need to think hard about how we communicate that to people.

People also spoke about the fear of making a complaint because they would initially have to go to the people or organisation with which they had had the bad experience to raise it. There was a real sense of fear of not having the ability to take that on while dealing with their illness. A sense came through in the comments that that was a particular issue for people who are experiencing mental health issues, whose strength really is depleted and who can struggle just to get through a day. To have to take on making a formal complaint as well was too much. However, the initial barrier of not knowing about the system in the first place is a big one.

Rachel Le Noan: I agree. There is an issue with the lack of information. People might have, in the past, raised concerns that were not taken seriously, so they ask what the point is in complaining. A crucial issue is that patients might not be ready to face another challenge on top of everything else. It can be upsetting to have to relive the situation about which they would like to complain. Therefore, there is something to be said for organisations such as ours to be consulted and taken more seriously. A complaints system might be in place, but many of our members have had bad experiences and never complained about them.

Derek Young: Through our helpline, we have experienced instances not only of people feeling that they are dissuaded from complaining but of people limiting their own desire to complain when they approach issues with the NHS. That is partly because they perceive that the professionals who are working in the system are dedicated, skilled and well-meaning but face system pressures. People do not want to feel that they are adding to the burden that those professionals face by complaining.

There are also different complaints processes for each of the territorial health boards, the State Hospitals Board, the Golden Jubilee Foundation Board, NHS 24 and the Scottish Ambulance Service. Therefore, if you had had a consistent difficulty over many different instances, you might have had difficulties with NHS 24, the Ambulance Service and then a particular health board. You would not want to have to make three different complaints under different processes and, if those complaints did not lead to a resolution that you liked, then have to escalate the matter to the Scottish Public Services Ombudsman.

10:30

We repeatedly hear that people dislike having to tell their story again and again. There may therefore be something in the idea that we should look at the structure and architecture of complaints handling in the NHS. It is important to point out that, as Carolyn Lochhead said, the vast majority of people report having experienced good healthcare.

Another important service is the patient advice and support service, which is run by Citizens Advice Scotland—I do not know whether it has come up in previous evidence to the committee. Our helpline advisers refer people to PASS as it is able to do some of the work of advising them throughout a complaints process and any potential review by the SPSO. When people use a service that is consistent and that they are sure of and can trust to be on their side, it notably improves their mood, especially if they feel vulnerable or are suffering with communication or cognitive difficulties, or if they feel that the system is much larger and more powerful than they are.

The Convener: What should be done to improve the system when things go wrong? We can be thankful that the number of people who are affected in that way is low in comparison with the vast number of people who receive a good service, but what kind of changes need to be made in order to make the system better?

Derek Young: I do not know whether that question was directed at me, convener.

The Convener: It was for anybody.

Derek Young: I will take the opportunity.

There must be opportunities for greater consistency in complaints handling or at least—although I do not wish standards to be written for the sake of it—for more standards on how complaints are dealt with or for principles that are applied consistently by all boards.

It would also help if there was a greater understanding and awareness among people of what happens when a complaint is made. A prime motivator for someone to pursue a complaint doggedly and persistently, as they might have to do, is the sense that it will lead to real change, whether for them or for others after them who may face similar clinical issues.

Carolyn Lochhead: I agree. It is really important to focus on ensuring that people know that they can make a complaint, how they should do so and—as Derek Young said—what will happen. It is important to look at someone's whole journey and identify the opportunities and touch points when they could be told about their rights, not just on making a complaint but more generally.

Everyone in Scotland who has a mental health problem has a right to advocacy, but that right is not well known or understood. If it was, and if advocacy was better funded—that is a slightly different point—that would help to address a number of the issues. Advocacy can be a great way either to resolve an issue before someone reaches the point at which they want to make a complaint or to support someone through the complaints process. A fundamental point is that people need to know what their rights are.

The Convener: Do people know what advocacy is?

Carolyn Lochhead: I do not know, but if there is a lack of awareness of the right to advocacy, it probably follows that there is a lack of understanding of what advocacy is.

The Convener: Are there any other comments on the subject?

Clare Ogden: Although complaints are valuable and there should absolutely be a proper process in place to deal with them, that must not be the only time when patients are able to share their views and experiences. Patients should be involved right from the beginning of service delivery, in the planning stages, and they should lead the work on what services should look like. That will, ultimately, probably lead to fewer complaints.

The Convener: Do we need a standardised—or, dare I say it, centralised—complaints system that is the same across the board, or is that too simplistic?

Rachel Le Noan: I would agree—anything that is standardised is quite helpful.

Our family support service has four officers who support families across Scotland. At 12 o'clock, they can be in one local authority area that has a particular complaints system, and at 3 o'clock on the same day they may be working in a different area that has a different complaints process. For the workforce, such as the people who advise families, it can be very tricky to remember all the different systems, so a standardised system might be good.

Otherwise, I simply repeat the point that I made earlier. Organisations such as ours could perhaps make better use of the evidence that we gather—in our case, from our family support service. The NHS could perhaps consult with us more on whether a particular service is working, as we may have evidence that could help it to improve. I do not think that every family will make a complaint.

Tom Arthur (Renfrewshire South) (SNP): Can I clarify something? A standardised system would involve a standard set of procedures that were followed by all the health boards and other bodies. A centralised system would be something different—an independent centralised system. You mentioned a standardised procedure. Do you suggest a standardised procedure or a centralised procedure?

Rachel Le Noan: I meant the same procedure across—

Tom Arthur: Something that is implemented by each body but is standardised and consistent.

Rachel Le Noan: Yes. That would make it easier.

Derek Young: There may also be an intermediate route, which would be to have consistency and standardised processes but a single initial place to which a complaint could be referred, which would then be directed to the appropriate board for it to deal with.

Tom Arthur: That would be an accessible portal.

Derek Young: Yes—a sort of one-stop shop. That might be an option.

The Convener: Ms Le Noan, you said that the NHS should speak to your organisation more. I presume that your organisation and the other organisations that are represented on the panel do not sit back and wait to be spoken to but speak up, lobby and submit to consultations—you do all the other stuff. I just want to be clear that you are not sitting back, waiting to be spoken to.

Rachel Le Noan: We are not. We are still a small charity compared with others. We can make written submissions, and it is important to recognise that smaller charities have knowledge that could be useful. We can try to contact organisations, but it can be difficult to find out who is leading on what and who is responsible for what. In terms of resources, it can be very time consuming for us to find out where we can go to to have the most impact.

There has, somehow, been a change in the past 12 months. For example, we have been invited to take part in the review of pregnancy screening, which is a big step for us. Today is the first time that we have given evidence to a parliamentary committee, which again is a significant step.

I just meant that there should perhaps be a bit more interaction, with people in the NHS contacting us, because it can sometimes be difficult for us to figure out who is the best person to contact.

The Convener: We are very pleased to see you.

Rachel Le Noan: Thank you.

Clare Haughey (Rutherglen) (SNP): I welcome the witnesses and thank them for making time to come along and see us this morning.

I want to pick up on what Clare Ogden said about patient and service user involvement in services and service development. All the written submissions to the committee from the NHS and integration joint boards state that service user involvement is a key goal, but the evidence from patient representatives differs somewhat. A number of the submissions criticise the NHS's approach to involving people in the development of services.

Action for ME says that about 84 per cent of patients had never been asked about their experiences of services, whereas 5 per cent were always asked, and Age Scotland says that there is

> "little evidence"

that involvement

> "is routinely and systematically happening at the planning level."

How can patient involvement in service development be improved?

Clare Ogden: There needs to be a real understanding of what the patient's needs are and how they might be involved at that level. Sometimes it comes down to accessibility. People with ME are not going to be able to make it to frequent meetings that last for hours and are in places far away from their homes. Improving people's ability to share their views and experiences in ways that work for them would really make a difference.

Carolyn Lochhead: There are two aspects to that involvement. There is the strategic-level involvement, which is to do with what services people need and what they want to see. Our survey showed that almost 80 per cent of people had never been asked what kind of NHS mental health services they want to see.

There is then people's more individual, day-to-day involvement in their own care. A Mental Welfare Commission report from earlier this year on acute admissions wards found that three out of four care plans were not sufficiently person centred. There is an issue there about individual care being based on an understanding of what people need, want, think and feel.

I would agree that, at a more strategic level, we need to think about the mechanisms and how we involve people. Often, things are done online. We do surveys online, and it is a good way of getting information, but we should not rely on that alone. The people we work with often tell us that they are not confident with technology. They would not fill in an online survey—they would want someone to speak to them. Instead of being asked to sit down at a computer or, as Clare Ogden suggested, being invited to a meeting miles away that will last for hours without anyone there to support them, they would like to be able to give their opinion via a service that they already use. We need to think about having a broad range of ways that people can feed in to the process. We also need to ensure that the process does not involve just the same people all the time—that it is accessible to people more broadly.

It is equally important to ensure that the focus of the individual care that people get is not just on giving them something or doing something to them. It should be based on that person's input, their experiences and what they want. The guidance makes it clear that that is what should happen but the evidence suggests that it does not always happen.

Derek Young: I echo some of Carolyn Lochhead's points. It is predominantly the role of the Scottish health council to represent patients in their interactions with the NHS. In the past couple of years there has been a programme to improve the channels by which patients can reflect on and help boards to better understand their experience. The programme is called a stronger voice, I think—I am not entirely sure whether that is right; if it is not, I will correct it later.

Individual patients are unlikely to want to get involved in decisions about the planning of services beyond their experience. That is where organisations such as ours start to get involved, and where we can contribute to discussions about standards, enforcement and so on. However, it is at the individual level where people really feel the greatest impact of being involved in decisions about their care. I can understand that that is a particularly sharp focus for people with mental health challenges. That is equally true for people who have cognitive or communication difficulties, because it is perceived to be more difficult to involve them in discussions and get them to give consent to treatment. We are pleased that the standards that now exist place far more emphasis on that, but it is still a very tricky area, where a lot of good professional judgment and sensitive treatment is required in assessing people's capacity. At the same time, the more pressure that staff in hospital wards are under, the greater the pressure on that approach. That is an on-going area of interest for us.

Jenny Gilruth (Mid Fife and Glenrothes) (SNP): My question is about Carolyn Lochhead's evidence. As you will know, NHS Fife is one of the five health boards in the country that have not yet met the waiting time target for child and adolescent mental health services. Clare Haughey alluded to patient involvement. We have heard previously from vulnerable groups—young people, for example—that they are falling through the gaps, particularly in terms of their mental health and the provision of care. Is there geographic inequality in patient involvement? Are some areas better than others?

Carolyn Lochhead: You mentioned the CAMHS statistics, which show clearly that there is geographic inequality in how quickly people are treated. We know that eight of the boards are currently meeting the CAMHS target—the evidence is clear. It is the same for psychological therapies. We have quarterly statistics that show that treatment within the timescales varies a great deal. Obviously, we would argue that a waiting time is only one part of access to a service. The quality of care that people get when they are seen and the outcome, which is rarely measured in any meaningful, strategic way, are equally important.

More broadly, it would be hard to evidence disparity in care in areas where we do not have such robust statistics, but we certainly hear from people that they feel that they waited longer than they expected to and longer than they feel is reasonable. The survey that we did involved a smallish number, but we had quite broad representation from across the country. To be honest, I would struggle to pick out one particular area where it looked like people were having a worse time.

Across the board, we hear of people's experiences of having to wait too long and push really hard to get a referral and treatment. Also—again, I cannot break this down geographically—people often talked about seeing a locum when they were not expecting to, or starting a course of treatment with someone and then having that person go on sick leave or maternity leave, or for some other reason not being there anymore. There is a point about consistency of people, and in mental health that is really important for building up trust and rapport. I suspect that there is geographic disparity in relation to those experiences, but I cannot point you to a source of evidence beyond the statistics that you mentioned.

10:45

Jenny Gilruth: Thank you.

Clare Haughey: I thank the witnesses for their answers to my question, but I am not really hearing a remedy; I am hearing lots of barriers and concerns about people's ability to drive service change or to input into service change. How do we get that patient voice heard, so that we develop services that are patient centred and which provide what the public want?

Carolyn Lochhead: We need to find methods of doing so that are accessible to people. They should not be based on the 9 to 5 working day for people who sit at desks; they should be based on what is realistic for people.

We also have to find a way to convey to people that their input is valued. I think that people do not always feel that it is. They feel that they are not consulted; even if they are consulted, they do not see the impact. We need to do something to make sure that when people have been consulted, there is feedback, so that they understand what happened as a result and what role their input played. I am not sure that that always happens. Letting people know the result of their having taken part and that they were listened to is very important.

Derek Young: At the moment, inspection takes account of how a service is delivered on the front line. There might be an opportunity for inspections to look more closely at how patient involvement and feedback happen and how that information is treated at board level, and for that to become a significant element of the reporting of inspections. Rather than looking at individual hospitals, inspections would look at board performance. There is no doubt that the inspection regime provides a dynamic that forces boards to articulate and justify the actions that they have taken. If that were to apply on an equivalent basis to management and leadership, which are critical elements of driving performance improvement overall, it might have some of the effect that you are looking for.

It is not about just people's ability to put their views across, or their confidence in feeling that they have an opportunity to do that; it is about what is done with those views once they are received.

Clare Haughey: Integration joint boards include a patient representative, who sits at that board level. The committee has heard evidence from some of those representatives about the difficulties and challenges that they face in that role. Do the witnesses know of any examples—good or bad—of how that role is developing within the IJBs?

The Convener: It seems that no one has an answer to that question.

Derek Young mentioned the Scottish health council. Have the organisations that the witnesses represent contributed to the on-going review of the health council's role? Do you have conversations with the health council about the patient voice and how it is heard, and how problems in the system can be made better? Does the health council ask for your view?

Derek Young: The main route for those discussions was through the standards reviews that I referred to. The Scottish health council was involved in the reviews of the standards for the care of older people and the new national health and care standards.

Through our helpline, we do not offer support to people in relation to their individual cases. Part of our role is just to inform people of their options and to signpost them appropriately. It seems that there is more opportunity for us to get involved in that, and we will certainly look at the review that you mention.

I also referred to the patient advice and support service, which is still located in the third sector, in citizens advice bureaux. We have had very positive feedback from people who have used that service, in terms of the assistance that it gives people who are pursuing their own complaints.

You make a fair point about whether system-wide involvement is working as effectively as it might be. We will certainly reflect on that.

The Convener: I would be surprised if, for example, the health council was not speaking to Scotland's main organisations for older people and for mental health issues about what it should be doing regarding this agenda. I would hope that that would happen.

Derek Young: We also participated in the stronger voice exercise. There are opportunities for us to improve that engagement.

Alex Cole-Hamilton (Edinburgh Western) (LD): We met representatives of the Scottish health council last year—it has been invited to a number of evidence sessions. Can the panel give us a view on its relative independence and its efficacy as a representative of the patient voice? I am bearing it in mind that when it consults on service redesign, it is acting on the advice of Government officials as to whether something is a major or minor service redesign, and it consults only on the major ones, even though patients may have a differing view as to whether that service redesign requires their input.

Clare Ogden: There are not sufficient services for people with ME in Scotland for there to be any redesign.

Alex Cole-Hamilton: That is a good point.

Clare Ogden: It is difficult for us to answer that question. One of the three services involves only a single individual—that is all the specialist provision that there is.

Derek Young: We have had limited direct involvement with the health council, so it is hard to answer the question. On the face of it, it sounds as if there could be a problem, if a service that people use falls on the wrong side of that distinction and its redesign is regarded as minor, according to the official advice.

Alex Cole-Hamilton: I move on to the impact of service redesign on the groups that you represent. Service redesign is naturally quality led, but the rigorous application of a quality framework can sometimes lead to unintended consequences for communities. Jenny Gilruth used the eloquent phrase "geographic inequality". Sometimes, surgeons or specialists are required to carry out a certain number of procedures to retain their accreditation. That then leads to service redesign, particularly for procedures relating to hips, knees and eyes. We have also seen that in relation to the cleft palate service that was relocated from the Royal infirmary of Edinburgh to Glasgow, even though patient outcomes were better in the ERI. Are you aware of the impact on the groups that you represent of the migration of services to the centre because of that stricture?

Carolyn Lochhead: Any service redesign can be difficult and distressing, although it can be improved when there is clear communication and discussion. Such things are much more difficult when people feel that something is just happening to them and they do not know what or why. Mental health policy is travelling in the other direction. There has been a commitment at Government level for a number of years to move from hospital-based treatment to community-based treatment, which is a direction of travel that we support, as long as it is properly resourced. Resources need to be moved from the acute sector to the community sector. I do not know whether the issue that you mentioned applies as much to our sector as it applies to others.

Alex Cole-Hamilton: I would imagine that it does not apply so much in the field of mental health. With regard to community resourcing for mental health, one in four doctor appointments is caused by an underlying mental health condition. Are you content that the Scottish Government's efforts to put link workers in surgeries will be sufficient to meet demand, given that those workers are not necessarily trained as counsellors and may not be able to offer talking therapies?

Carolyn Lochhead: We are supportive of the move towards link workers, but we need to be aware of what they are and what they are not. In some areas, link workers are mental health specialists, whereas in other areas there is a generic link worker service. In such a service, the link workers can discuss any health issue and their job is to be sufficiently rooted in the community that they can direct people to all kinds of community assets. The link workers initiative is good and we are supportive of it. Indeed, we have a link worker service, but, as with any service, we have to be aware of its limitations. Link workers can be effective in giving people more time and space to talk through their issues than a GP can, and to go a little further with them. For example, if it is suggested that physical activity would benefit a person, they can facilitate an introduction to a local service, and they may even accompany the person to their first appointment. They can, therefore, be effective, but they are not sufficient as a mental health service. We need much more as well.

Alex Cole-Hamilton: Is there a concern that the link workers might establish with the patient that a certain intervention is required but that intervention might not be available in the locality?

Carolyn Lochhead: The job of a link worker generally is to know what is available in their locality and to refer to that, so that is unlikely to happen. In fact, in some areas, link workers can drive improvement. We have a service in Inverclyde that is not formally a link worker service but is similar, and it has driven improvement. Because a gap was identified, there are now college courses that are specifically designed for people with mental health problems, which did not previously exist. There is the potential for gaps to be identified and filled through link worker activity.

Miles Briggs (Lothian) (Con): Good morning, panel, and thank you for your written submissions.

I want to move the conversation towards the families of individuals who are trying to access care and how they are treated and listened to—or not. We have taken evidence from a number of people who, in trying to support younger people, have raised complaints but have been pushed back. What is the culture around the family who are supporting an individual? In your experience, are people's families listened to?

Rachel Le Noan: It will come as no surprise that our report showed that a lot of parents describe themselves as fighters. In many cases, from the moment that a baby with Down's syndrome is born, the parents have to fight for everything from education to healthcare. It should not be like that. People should not have to fight or have the feeling that they are competing with healthcare professionals. That goes back to the point that we made at the beginning of our evidence, about the lack of dignity and respect. We heard from parents that their concerns are not being listened to. Our family support service has reported that, when parents make a complaint, they are sometimes described by healthcare professionals as "difficult" or "emotional". That is wrong as well.

There are a lot of issues to do with support for families and actually listening to them. Many families will have had good experiences, but the fact is that a lot have not. There is also an issue about the provision of information. For example, our report showed issues with the provision of information on annual health checks for adults with Down's syndrome—50 per cent of the carers of adults did not know about the recommended health checks. Information needs to be provided to families at the right time so that they can make the choices that they want to make.

Clare Ogden: A huge number of people with ME are cared for by family members. People with ME find it extremely difficult to get social care provision. They have to be extremely severely affected, and even then it is tough for them to get it. Similarly to what Rachel Le Noan described, the parents of children with ME would describe themselves as fighters.

A recent survey—it was mostly of families in England, although we have no reason to think that this is not happening across the UK—found that one in five families of children with ME is subjected to child protection referrals, although most of those do not go anywhere. Things that would normally be a red flag, such as a family not sending a child to school or not letting them see their friends, are normal for children with ME but, because people do not understand that, families are being threatened with child protection referrals. That is extremely concerning and it puts a lot of pressure on people who are already under great strain.

Carolyn Lochhead: I will take a slightly different angle. Parents of young people who were severely ill and suicidal have spoken to me about their son or daughter being discharged into their care with very little support or even guidance on how to keep them safe. It is a terrifying experience for a parent to feel that they have that responsibility and do not have support or backing, although, of course, they try and want to do their best. I have heard that from more than one parent.

Derek Young: In our case, it is mostly not the parents of people who are receiving treatment who are the family member concerned; it is often the children. There is anecdotal evidence that most of the calls to our helpline about health services are from the children of the people who are patients in hospital, who are struggling to get information and have a productive interaction with hospital staff, who have far less time to engage with them.

11:00

On a related issue, there are also difficulties when an older patient is suffering communication or cognitive challenges, because it is often their adult child who is used to advocating for them and organising personal things on their behalf. However, their status as next of kin comes into play only at certain points in the health process. If there are severe cognitive challenges, they might already have welfare power of attorney or have a guardianship order under the Adults with Incapacity (Scotland) Act 2000.

It has been reported to us that there is sometimes poor understanding of those particular frameworks and of how powers of attorney and guardianship orders operate. That is sometimes to do with the fact that staff do not get a lot of time or support for training on adults with incapacity issues. A lot of people have learned the skills through an e-learning module and they are not provided with separate working time to complete that module. The training is done in order to be seen to be done, but we have not had a lot of evidence that there is widespread understanding of how it impacts on day-to-day care. That obviously impacts on how those family members interact with the professionals.

Miles Briggs: My next question might need just a yes or no answer. Do you think that there is a culture in the NHS of trying to discourage or limit the number of complaints from families?

Derek Young: I do not have enough evidence to say that there is such a culture, but there are certainly indications of it, and that is worrying for us.

Ivan McKee (Glasgow Provan) (SNP): My question neatly dovetails with Miles Briggs's last question. I want to ask about process improvement separate from the complaints process. People who have a bad experience will go through a complaints process. However, because of the care that they have experienced or what they have seen, people will often say things like, "If you did this, it would be better." People often say that they do not want to make a complaint but that improvements could be made. They ask why they keep getting medicines that they do not need and that are thrown in the bin; why the food comes at the wrong time so that it is always wasted; or why X, Y or Z happens. There are lots of examples of that.

Does the health service deal with that well, or is the culture such that, as soon as anybody says anything, the health professionals become defensive and start to talk about how to stop someone suing the hospital or how to deal with them? A mature organisation looks for opportunities for improvement; do you have a sense that the health service does that, or is it too defensive?

Clare Ogden: We do not see much evidence of that. People with ME often feel that they are not heard by the health professionals whom they see. There are some fantastic health professionals out there—I do not want you to think that I am saying that there are not—but the stigma that is attached to the illness and the lack of understanding and awareness about its impact, not just in health but across core services, add to the culture of people not being listened to.

Carolyn Lochhead: When there has been a serious event, such as a suicide or an attempted suicide, we do hear that things start to feel defensive. When it comes to what you were asking about, which I think was on-going feedback on more minor—

Ivan McKee: It can cover the whole range of events, from major to minor.

Carolyn Lochhead: I would not say that I hear much about people being defensive. This is a personal view but, rather than being able to point to a source of evidence, I wonder whether the channels exist to ensure that such informal feedback, which is not fed through a process, can get to where it needs to go. That is why I might be concerned.

Derek Young: Similarly, I do not have specific evidence that I can point to about the extent to which there is a defensive reaction in health boards.

Let us think about it in human terms. If the low-level, small or minor suggestions about improvement are acted on and there is no complaint, the problem might not be formally documented in the system. The difficulty from the health professional's point of view is that we are not evidencing success very well. If that was documented and highlighted for the benefit of staff, it might help to shift some of the attitudes that staff have towards the complaints process and show it as being an opportunity to highlight and drive service improvement rather than just an external accountability-focused process.

When complaints are dealt with as an opportunity rather than a difficulty or a challenge, that is a real driver for service improvement. That is seen not just within the health service but in other areas of public service.

Rachel Le Noan: I agree with what has been said. It is about the process and how we capture those stories if a proper complaint is not made. For example, in a service that might not see many people with Down’s syndrome, if two adults out of 1,000 asked for more time to speak to the doctor, would the fact that they had Down’s syndrome be taken into account or would the service say that it was just two people and stick to what it usually did? That is one of the questions that I would have.

The Convener: We are out of time. I thank you for coming along this morning—it is much appreciated.

11:06

Meeting continued in private until 12:33.

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