The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 4 March 2014

Session 4

Tuesday 4 March 2014

CONTENTS

HEALTH AND SPORT COMMITTEE

7th Meeting 2014, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

*Bob Doris (Glasgow) (SNP)

COMMITTEE MEMBERS

*Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
*Aileen McLeod (South Scotland) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Gil Paterson (Clydebank and Milngavie) (SNP)
*Dr Richard Simpson (Mid Scotland and Fife) (Lab)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Dr Ishaq Abu-Arafeh (Royal College of Paediatrics and Child Health)
Dawn Crosby (Teenage Cancer Trust)
Jean Davies (Royal College of Nursing Scotland and Strategic Paediatric Educationalists & Nurses in Scotland)
Sheena Dunsmore (Kidney Kids Scotland)
Yvonne Hughes (Cystic Fibrosis Trust)
Jane-Claire Judson (Diabetes UK Scotland)
Margaret Kelman (Children and Young People's Allergy Network Scotland and NHS Lothian National Managed Clinical Networks)
Dagmar Kerr (Action for Sick Children Scotland)
Scott Read (ARC Scotland – Scottish Transitions Forum)
Dr Stan Wright (Royal College of Physicians of Edinburgh)
Colin Young (Health and Social Care Alliance Scotland)

CLERK TO THE COMMITTEE

Eugene Windsor

LOCATION

Committee Room 2

Scottish Parliament

Health and Sport Committee

Tuesday 4 March 2014

[The Convener *opened the meeting at 09:48*]

Decision on Taking Business in Private

The Convener (Duncan McNeil): Good morning and welcome to the seventh meeting in 2014 of the Health and Sport Committee. As usual, I ask everyone in the room to switch off mobile phones and BlackBerrys, and I give notice that some members and officials are using tablet devices instead of hard copies of their papers.

I ask our guests for the round-table discussion to bear with us while we briefly go through some other business.

The first item on the agenda is a decision on whether to take in private item 5, which is consideration of the evidence that we heard last week on access to new medicines. Does the committee agree to take item 5 in private?

Members *indicated agreement.*

Subordinate Legislation

Infant Formula and Follow-on Formula (Scotland) Amendment Regulations 2014 (SSI 2014/12)

09:49

The Convener: Agenda item 2 is consideration of three pieces of subordinate legislation. On the first of these three negative instruments, no motion to annul the regulations has been lodged and the Delegated Powers and Law Reform Committee has made no comments on them. If members have no comments, are we agreed that the committee has no recommendations to make on the regulations?

Members *indicated agreement.*

Self-directed Support (Direct Payments) (Scotland) Regulations 2014 (SSI 2014/25)

The Convener: No motion to annul the instrument has been lodged, but the Delegated Powers and Law Reform Committee has drawn the Parliament’s attention to it for the reasons detailed in the paper before members. If members have no comments, does the committee agree that we have no recommendations to make?

Members *indicated agreement.*

National Assistance (Sums for Personal Requirements) (Scotland) Regulations 2014 (SSI 2014/39)

The Convener: No motion to annul the instrument has been lodged and the Delegated Powers and Law Reform Committee has made no comments on it. If members have no comments, does the committee agree that we have no recommendations to make?

Members *indicated agreement.*

Transitions from Paediatric to Adult Services

09:51

The Convener: Our main item of business is agenda item 3, which is a round-table evidence session on the transition from paediatric to adult services. As usual with round-table sessions, I will begin by introducing myself and will then invite the others around the table to introduce themselves.

I am Duncan McNeil, MSP for Greenock and Inverclyde and convener of the Health and Sport Committee.

Dagmar Kerr (Action for Sick Children Scotland): I work for Action for Sick Children Scotland.

Bob Doris (Glasgow) (SNP): I am an MSP for Glasgow and the deputy convener of the committee.

Yvonne Hughes (Cystic Fibrosis Trust): I am from the Cystic Fibrosis Trust.

Jane-Claire Judson (Diabetes UK Scotland): I am the Scotland director of Diabetes UK.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I am an MSP for Mid Scotland and Fife.

Sheena Dunsmore (Kidney Kids Scotland): I am from Kidney Kids Scotland.

Colin Young (Health and Social Care Alliance Scotland): I am from the Health and Social Care Alliance Scotland.

Colin Keir (Edinburgh Western) (SNP): I am the MSP for Edinburgh Western.

Jean Davies (Royal College of Nursing Scotland and Strategic Paediatric Educationalists & Nurses in Scotland): I am a children's senior nurse with NHS Ayrshire and Arran. This morning, I am representing the Royal College of Nursing Scotland and the strategic paediatric educationalists & nurses in Scotland group.

Richard Lyle (Central Scotland) (SNP): I am an MSP for Central Scotland.

Dr Ishaq Abu-Arafeh (Royal College of Paediatrics and Child Health): I am a consultant paediatrician, representing the Royal College of Paediatrics and Child Health.

Dr Stan Wright (Royal College of Physicians of Edinburgh): I am a consultant in respiratory and general internal medicine, and I am representing the Royal College of Physicians of Edinburgh.

Rhoda Grant (Highlands and Islands) (Lab): I am an MSP for the Highlands and Islands.

Scott Read (ARC Scotland – Scottish Transitions Forum): I am a development worker for the Scottish transitions forum and I am representing the Association for Real Change.

Aileen McLeod (South Scotland) (SNP): I am an MSP for South Scotland.

Dawn Crosby (Teenage Cancer Trust): I am from the Teenage Cancer Trust.

Nanette Milne (North East Scotland) (Con): I am an MSP for North East Scotland.

Margaret Kelman (Children and Young People's Allergy Network Scotland and NHS Lothian National Managed Clinical Networks): I am the CYANS paediatric allergy national managed clinical network manager. CYANS is the Children and Young People's Allergy Network Scotland. I am also representing NMCNs for NHS Lothian.

Gil Paterson (Clydebank and Milngavie) (SNP): I am MSP for Clydebank and Milngavie.

The Convener: Thanks for that. I ask Nanette Milne to open the discussion.

Nanette Milne: Just to set the scene, I believe that a number of you around the table will know that I am involved with quite a lot of cross-party groups on health-related topics. It has been made loud and clear to me that there are issues with the transition from paediatric to adult care in a number of chronic or long-term conditions, and I thought that it might be a good idea—and the committee agreed—to have a session like this to hear views from a number of interested parties.

From the written submissions, it is obvious to me that they have views in common. I have picked up that transition is a process, not a single event, and that it should be patient centred and planned. There seems to be a lack of meaningful information for young people who are moving from childhood to adolescence and then to adulthood. It has also been suggested that having a key person would be important to support and guide those young people through the process, and the issue of facilities has also been raised. Is that a fair summary of what most of you think on the issue?

In your submissions, you have also made some suggestions about the best way forward. At this point, I will ask a question that would normally be asked at the end of this kind of session—and I might ask it again at the end of the discussion to find out whether your views have changed. Is there any single action that could be taken that would bring about immediate positive change for the transition from paediatric to adult services? I ask you to think about that as you respond. I am also interested in your views on the transition process and what you think is important in that regard.

Dagmar Kerr: It is obvious from the written submissions that we are all singing from the same hymn sheet; indeed, I think that we have been singing from the same hymn sheet for more than 20 years.

Action for Sick Children thinks that the way forward would be for every health board to have a person with the remit of overseeing the transition. That person would have to have enough influence over governance to ensure that everyone involved, particularly adult professionals, complied with the copious guidance that already exists.

Dr Wright: I welcome the chance to discuss the issue. Having been a consultant for 25 years, I know that the transition from paediatric to adult services has been a problem throughout that period.

It is worth pointing out what tends to be the norm. Some conditions are managed better than others—for example, cystic fibrosis tends to be managed better than many other conditions—but, as the submissions state, the patients do not go through a process. Instead, they tend to get a handover.

In many ways, the adult service is completely different from the paediatric service. The transition takes place when patients are going through the physical and emotional changes of puberty and whereas previously their parents would probably have made many decisions these young people enter a system in which they have autonomy. We have to respect the fact that, once they are in the adult system, they make the decisions, but sometimes those who have been their carers for many years do not agree with those decisions.

I agree that the first thing that should happen is that each health board should set down a process for how the transition should take place and that someone should be made responsible for ensuring that it is done well. I do not think that that will happen overnight, because there will be resource issues, the biggest of which is time. It takes time to see such patients. Invariably, they get referred to the out-patient clinic and we have to sort out the issue there and then. The transition is not handled at all well.

Dr Abu-Arafeh: If there is one thing that we should look at to determine how the process should end, it is the setting of standards. At the moment, transition takes different shapes and forms; sometimes it involves local initiatives and at other times it involves personal initiatives. Quite often, those approaches are unreproducible from one area to another. The health department probably has a role to play in working with professionals and professional organisations to set the standards that we want to achieve, and a lot of energy is being expended on that.

When we looked at child protection, we did so on the basis of our own experience and our own work. However, when standards are set, practice becomes uniform all over the country and the process becomes much better managed. In my view—and in the view of the Royal College of Paediatrics and Child Health—we have to set standards, and we can work with any organisation or any official department such as the health department to set the standards for transition.

One problem is the perception that the purpose of the transition is to replicate the paediatric model of care in adult services. That should not be the case; instead, it should be a growing-up process. Adult services should adapt to the needs of the young adults and paediatric services should adapt by promoting growth and the taking on of roles and responsibilities. We do not want just an extension of paediatric services into adult life.

10:00

Scott Read: A number of issues arise with transitions. Although I find it extremely heartening that this discussion is taking place within healthcare, I point out that transitions take place across all aspects of a young person's life. They happen in education; in social care, if a young person needs such care; in the benefits system; and in housing.

There is a whole raft of legislation that should drive what are called in education the positive destinations. For example, there is the self-directed support agenda and the Public Bodies (Joint Working) (Scotland) Bill—or what might be called the integration bill—which looks at ways of combining those different organisations in healthcare. We must be aware that transitions happen across a raft of different areas at the same time and that this transfer is a difficult time for children and young people, especially those who have exceptional healthcare needs.

An associated issue is a lack of resources, which the integration bill sought to amend. However, any decision that is taken from a health angle must take into consideration what is happening in the different areas of legislation and pull all that together.

One of the biggest issues is the change in assessment processes. We have a very personalised way of looking at children—the getting it right for every child approach that was embedded in the Children and Young People (Scotland) Bill—but that approach stops when a young person becomes an adult. As we change the assessment language in children's services, it might be a bit difficult to match up that approach with adult services and to provide a team around a child that will continue into adulthood.

Jean Davies: I concur with what my colleagues are saying.

One of the most immediate and most difficult issues relates to children who have complex or exceptional health needs. There is a group of children who have multiple problems. At present, they are subdivided into body systems, which is not helpful. They have one paediatrician. Although the paediatrician will refer to many specialists, the care co-ordination comes back to them.

The general practitioners might be aware of those children, but sometimes they are not. In some cases, that is because our systems mean delays in the GP getting important letters and so on. When we are looking for someone else to co-ordinate the care, the family is usually the main carer. Quite a high percentage of children who have multiple complex needs can end up in the looked-after children system, which presents its own issues. More often, we see youngsters who have learning disabilities or who are on the autistic spectrum. During adolescence, those children become very difficult for their families to manage at home. They might find themselves having long hospital stays and then being put into a residential educational establishment. There are many complex issues around that particular group of children, because there are not comparable clinicians to whom they can be handed over, let alone be given a proper transition.

Many children have told us heartbreaking stories about how they just felt that they did not know where they were going and that no one cared, and how they voted with their feet and did not go to appointments. Those were the articulate children and young people, but the ones who have no voice because they are unable to articulate their feelings and do not have the right advocacy are left without services and without being able to tell us about the services that they require.

Colin Young: To build on Scott Read’s point, we need a common-values approach across all three services, because narrow definitions of outcomes for disabled children mean different things in different settings. In education, it means getting on and going to college or extended education. In social care, it is about independent living, or living with some sort of support. In health, it is often about maintaining their condition or trying to cure some sort of health problem.

For people with long-term conditions, outcomes are not about curing or maintaining, but about ensuring that children have the right support to enable them to live whatever life they would like to live. Throughout paediatric services, there is an emphasis on encouraging growth from a medical point of view.

However, if we changed the values to look at what children want out of their adulthood, it would fundamentally alter how we approach child health. We would then be trying to ensure that children grow up to be adults in an environment that is supportive of their ambitions, rather than simply trying to maintain the status quo of their health condition.

Sheena Dunsmore: I can speak only from a renal point of view, but I spoke to quite a few of the children with whom we deal, and they felt that one door had closed but another had opened, and that they had left what was essentially a family atmosphere to come to a place where hardly anybody spoke to them. If they were confident, they could get on with it, but if they were less confident, they found life difficult. At a time when medication is important and they are vulnerable, they should have some support from the adult side.

Jane-Claire Judson: I would like to build on the points that Dagmar Kerr and Scott Read made about responsibility and accountability, and the philosophy involved. In preparation for today’s meeting, we asked our young people and some healthcare professionals to give us feedback on what they thought about the transition.

One young person said that she had had her first appointment at an adult clinic in the past few weeks. Her story was quite upsetting for us to read. She turned up at the adult clinic and nobody even referred to or acknowledged the fact that it was the first time that she had been to an adult clinic appointment, so the welcome was not particularly warm and, as you can imagine, she was quite nervous about that first appointment. She had also done a lot of preparation for the appointment but was told that it was not in the format that the adult clinic preferred, which, for someone who was taking control of her condition, managing it and being responsible, was quite distressing and upsetting.

That example tells us something about the philosophy. That person’s move from one service to another was a transfer, not a transition. We could try to pull the philosophy from paediatrics through into adult services, but there is a question about responsibility and accountability. Who is there for a young person to talk to about such an experience? They need to be able to talk to someone, knowing that that conversation is in confidence and that it will not affect their on-going care. They will certainly not go through a complaints system for that; it is a different type of conversation.

We also had feedback from a healthcare professional who, as a member of paediatric staff, was concerned about the philosophy and about allowing young people with diabetes to go into the adult system. It must be upsetting for a healthcare professional who has built a relationship with a person to know that they could be sending that person somewhere harmful that will not support them with their condition.

We need to think about the concept of adolescence and the emerging adult. When I was doing some reading the other day, I noticed that JRR Tolkien was one of the first people to use the term “tween” in the 1930s, so it is not a new concept, although I think that our definition of it is slightly different. He saw it as the stage between childhood and a person’s early 30s. He defined the end point as 33, so he was quite specific—I am not sure that we would want to be quite so specific. It might be different for different people. We definitely have to consider how an individual has developed and whether they feel that they are ready to take on responsibility. We also have to look at the emerging evidence about how our brains develop and how we develop as people.

Nanette Milne asked what single thing could be done. I think that it is a combination of what Dagmar Kerr and Scott Read said. We have specialist staff for medical support. For diabetes, we would want a diabetologist or a paediatric diabetes specialist nurse, and we would want similar staff for other conditions. However, I have yet to see the use of other specialists embedded in paediatric and transition services. I would urge the national health service and other services to consider using youth engagement specialists, who understand how to support young people to engage, advocate for themselves and talk about what they want from their care. I do not see multidisciplinary teams in the NHS bringing in services from outwith the NHS that could really help support young people in that transition process.

Nanette Milne: I want to follow up on that. Diabetes UK has an interesting statistic on people disengaging from services, which Jane-Claire Judson mentioned at the most recent meeting of the cross-party group on diabetes. They may well disengage if they have an unsatisfactory transition between adolescence and adulthood, and re-engagement might not happen for many years thereafter. I think that she said that it might be almost 50 years before they engage properly with services again. Obviously, with a condition such as diabetes, many things could go wrong in that period.

Jane-Claire Judson: One of the things that we realised was that our assumption about when young people might disengage from a service was inaccurate. We thought that they might disengage when they were 17 or 18—the age that we might consider to be the most difficult for an adolescent—but the research showed that people are more likely to start disengaging in their early 20s. The curve drops to about 30 per cent disengagement and engagement levels do not rise again until people are essentially at retirement age, so they are losing a great deal of support through engagement with the NHS for their whole life.

One of our young people pointed out that they were not disengaging from their condition. A young person with diabetes cannot disengage from their condition—they have to manage it or, as that young person put it quite bluntly, they would be dead within weeks—but they can disengage from services. We have to ask why they would want to do that. They are managing their condition the best they can on their own, but why can we not attract them to use services that would support them?

Margaret Kelman: On transition for young people with allergy, in a lot of places in Scotland there are no comparable allergy services for adults. Kids go from paediatric services out to primary care, because there is no secondary care adult provision. Only two areas in Scotland provide those adult services. Jane-Claire Judson talked about disengaging from the service, but those young people have nowhere to go.

Most cases of fatality through allergy happen to young people. Research shows that that maybe relates to risk taking. As Jean Davies said, we need to look at having comparable services for adults. If there is no funding for comparable services, we need to see whether other specialties are willing to take on those patients as adults and provide them with a service, so that they can be transitioned.

10:15

Dawn Crosby: Nanette Milne asked what single thing could be done. We are kind of lucky in the cancer sphere in that we have adolescent services for people through to their early 20s. Having an age-appropriate multidisciplinary team that is carried through that age group can pose its challenges, but it can also provide opportunities. There are a couple of pockets of good practice in Glasgow and Edinburgh that see the young person through the transition process.

That is predominantly down to the nursing, but it is also down to clinicians on both sides—I say both sides because it sometimes feels as if there is a paediatric side and an adult side. Scotland’s biggest opportunity is to bring those sides together, and adolescents are the ideal age group with which to do that. The way forward is to have interested clinicians and key clinicians around the table discussing the patient as a person as opposed to a disease. You guys need to look at the pockets of good practice and see how it can be replicated across Scotland.

Dagmar Kerr: I say to Dawn Crosby that one of the big pluses that you have in your cancer pocket is that you engage a lot with the third sector, and that education is available. Scott Read made the important point that we cannot look only at the medical problems, because education and psychological support are very important. None of the issues can be seen in isolation.

Scott Read: I agree with what Dagmar Kerr said. Due to the additional support for learning datasets, there are rafts of information about who is coming through schooling with additional support needs. That information provides a good way of looking at everybody who might need some support when they are at school, as it captures the whole raft of issues.

On engagement with external agencies, 45 per cent of those young people were engaged with by health when they were at school. It would be very interesting to see how engaged they were with health when they left school. I highlight again that transitions is a multidisciplinary team issue for children who have some additional support needs.

Jean Davies: I will respond to Nanette Milne's request for us to come up with a single action that will help.

Taking into consideration what has just been said, although we can do something in nursing, we also face a challenge in nursing. In my health board, which pledged to do something about transition, we looked at the middle range of transition, from 14 to 18 years of age, and held joint diabetes clinics, where we brought together the paediatric diabetes nurse and the adult diabetes nurse. When we reflected on the issue, we felt that the age group that we probably needed to address was 14 to 23 or 24, rather than 14 to 18. To do so, we would like to provide joint education and training for paediatric nurses and adult nurses.

However, there are challenges around what nurses have been trained to do and the age group that they are qualified to look after because of how they are registered with the Nursing and Midwifery Council. Advanced nursing practice courses, which are sponsored by NHS Education for Scotland, might provide a solution. If we could get paediatric practitioners and adult practitioners to pick up the advanced practice modules and qualifications that are available, they could look after young people across the whole age range who need not only diabetes care but all care. That might be a solution.

Dr Wright: I recognise much of what has been said because I have heard it so often. As with a lot of the problems in medicine, it comes down to communication.

I hear what Jane-Claire Judson says about the young person turning up at the adult clinic for the first time. However, the adult clinic may not know what has gone on beforehand or that it is the first time that the patient has been told to go to an adult clinic. The clinic is therefore seeing somebody who is not prepared for what will happen. It probably does not even know an awful lot about the condition, given that patients are now surviving with conditions that used to be seen only in paediatrics. We did not use to see conditions such as endocrine and neurological diseases in adult clinics. We struggle with that.

Although the adolescent tends to get referred to the specialist who deals with their dominant condition—a respiratory physician in the case of cystic fibrosis, for example—they will have other comorbidities. In modern medicine these days it is very difficult for someone to be knowledgeable about everything. The fact is that, when various psychological elements and issues of sexuality, fertility and so on are put into the mix, doctors are simply not trained to deal with the situation.

I think that we can learn from the approach that is taken to cancer care. I was the lead cancer clinician in Forth Valley, and one of the things that we did to get around the communication problem was to make it clear that it was sometimes very difficult for doctors to provide continuity of care and that that role could be carried out by cancer nurse specialists. Adolescents need someone who regards themselves as responsible for them, and at the moment that is difficult. That person does not have to be the consultant; it could be the nurse or whoever, as long as they feel responsible.

My final comment goes back to Scott Read's point about the need for a multidisciplinary approach. Healthcare would welcome a multidisciplinary meeting with social care and education and occupational services perhaps every six months or so, at which a responsible person could put forward the adolescent's problems—in fact, the adolescent themselves could attend and tell the various services their problems—and those involved could then discuss the matter with other professionals and say to the adolescent, "This is what we would advise you to do. How do you feel about that?" I simply do not think that referral to one person in one service will work.

The Convener: I presume that everyone around the table will agree with Dr Wright's comment that the issues have been under discussion for 25 years. Much of what we have been discussing with regard to hospital services for young people was addressed in “Better Health, Better Care” in, I think, 2009 and again in 2011. However, we have heard around the table this morning that things are just not happening in practice. We might come on to discuss basic gaps and failures in the system, our expectations of it and why things are not happening in every health board. Surely we need to examine some of that before we get to the aspirational stuff that we have been talking about for 25 years.

Can you take up some of that, Bob?

Bob Doris: I will probably not be able to solve those issues in the next 30 seconds, convener.

Having listened carefully to the discussion, I think that all my questions have been half-answered. However, the comments from Scott Read and Colin Young about the need for a multidisciplinary approach to transitions and the multilayered nature of young people’s lives jumped out at me. All young people, including those who do not have healthcare needs, have to deal with a range of transitions as they grow up and, as Dr Wright has pointed out, there will also be a whole series of transitions in relation to the healthcare needs of young people who have multimorbidities.

When, at the start of this discussion, Nanette Milne asked everyone what one thing would help the situation, the idea of an individual responsible person for transitions was mentioned. I am slightly unclear about how that would work. People come to me to discuss a variety of social care transitions, but I have to say that they rarely come to me to discuss health transitions. Quite often, families come to my surgery to discuss a young adult child who is leaving educational services. That young adult was looked after and empowered five days a week, but now the council is giving them two mornings a week at a day centre. Those families have young people with hugely impacting conditions who are now at home five days out of seven, and the families tell me that they just cannot cope. Given the inextricable link between health and social care, does it matter whether the responsible person is a healthcare specialist, a social care specialist or an individual who knows the system and the networks and punts for the young person through a whole series of transitions? A little bit more information on that would be quite useful.

As a teacher for 10 years, I know that in schools one of the most basic things that happens is that, to prepare kids for the move from primary 7 to first year in high school, high school teachers go into P5, P6 and P7 classes to talk to the kids, and the kids themselves visit the high school. Every school seems to be excellent at that. Can you give examples of similar good practice in overlapping service provision? Before young people with particular conditions move to adult services, is there any overlapping that allows them to get to know those services? I am bearing in mind the fact that some of you are talking about the need to tweak and redesign adult services so that there is a better fit with transition.

I know that I am asking more questions, but it struck me that I should also ask who the best individual would be to have responsibility for all transitions in a young person’s life. How could that be taken forward? Are there examples of good practice?

Dagmar Kerr: You are looking for two different people. One person would be the key worker for an individual and could come from social care, health or education—although I always think that individuals from education drop off a wee bit once the child has left education.

The other key role that I was talking about would involve somebody in each health board overlooking transition. NHS Greater Glasgow and Clyde had somebody in that role, although they are retired now. Such a person would look at and perhaps develop adolescent or transition policies for the board. We need somebody who has enough governance power, if you like, to ensure that people in adult hospitals or healthcare centres adhere to those policies. You are looking to have two different people: one who is responsible for an individual transition, and one who looks at the structure and philosophy in each board.

There has to be a huge culture change. For example, we have adolescents ending up in adult wards where staff might see them as a threat. I have a very silly example. A nurse on an adult ward came to change the catheter of a 15 or 16-year-old male who made a silly, adolescent joke about where she was putting her hands, and the nurse was highly offended at that inappropriate behaviour. Such situations just require very basic learning about how to deal with adolescents. There could be a policy change so that all adult professionals underwent such training regularly.

Dr Abu-Arafeh: We are talking about who is responsible and who is a key worker. We have alluded to children with complex needs and significant major health, social and educational problems. Luckily, they are the minority, although we should not underestimate their needs. The majority of children can probably be their own key workers. Quite a lot of them grow beautifully into adolescence and adulthood.

Yesterday, I had in the clinic two 16-year-old children who wanted to be seen without their parents. That is the process of empowerment for most children—they were primary school children who were brought into the clinic by their parents, but they grow up and, as they grow older, some of them take more responsibility for their conditions and treatment. They need to be empowered, encouraged and educated; if they are, they will probably transition smoothly and well. Our responsibility, as healthcare providers and social care providers, is to make that happen—to enable the child to take responsibility. That can be done with the vast majority of patients.

However, we do not want to replicate for primary school children the service that we provide for infants, and we do not want to replicate for adults the service that we provide for secondary school children. The process has to be progressive. That is what we mean: the process has to increase responsibility progressively. However, for some kids, somebody else has to take the responsibility, whether that is their parents or a health worker, a social worker or another key worker whom they feel most comfortable with.

Yvonne Hughes: I back up what Jean Davies said. Our charity says that the transition period is from 12 to 20 years old. People with cystic fibrosis are probably quite well supported. We have joint clinics, and our nurses also visit families in their home. There is more support in that regard. Bob Doris asked about what nurses can do. I agree with Dagmar Kerr that there should be two key people.

10:30

Scott Read: I will follow up on Bob Doris's comment about transitions workers. Back in 2006, the Care Co-ordination Network UK considered in detail the key worker model, which was then adapted to become the getting it right for every child model, which in turn became the named person, whose role is up for debate at the moment. I know that the members of the Scottish transitions forum do not see the role of the named person as being a key working role at all; they view the named person more as a gatekeeper for other services.

Dagmar Kerr commented about the role of the transitions co-ordinator, which is needed for some children who do not have the necessary self-efficacy or self-empowerment and who need somebody to work with them at the family level from the age of 14 until they transition. Not everybody is lucky enough to have parents who can empower them and go through situations with them in a way that equips them to deal with those situations.

I will give one very good example. The transitions co-ordinator in NHS Highland is contracted through education but paid via health and social care budgets. Their job is not really a key working role, as it has been adapted to the extent that they are able to go anywhere and untie the knots in transitions for any young person they come across. They are very much aware of health, social care and education legislation—that mirrors their contract and how they are employed. Highland has become quite integrated in how it funds various posts.

I do not know whether that answers Bob Doris's question.

Jane-Claire Judson: I have thought of an additional point regarding Bob Doris's question about what we mean by a transitions co-ordinator or a responsible person. Having such a person in a health board might allow the third sector to engage and provide support more systematically. It might give us a point of contact, so that we do not always have to go directly to front-line NHS services, which can be difficult, as it involves asking clinicians to take on more and more development work.

I was also thinking through the idea of how a young person views their service and the person they see as managing their health, whether that is a key worker or the person they feel closest to. We need to take that into account.

About a year ago, I had a discussion with a paediatric consultant who told me about a young woman who had come to him to ask about contraception and how it might affect her type 1 diabetes. His response was, "I don't know. I'm not trained in sexual health." He did not know why he was being asked that question. My challenge back to him was that that was a perfect opportunity to engage positively with that young person about her life and her health, to signpost services and to support her. Although that healthcare professional did not see himself as being in that role, that young person did. She had identified that consultant as somebody she could trust and have confidence in to help her.

The issue is one of examining those roles and how people see them. Someone might not be the appropriate expert with a complete understanding of an issue, but they have an opportunity to signpost people to the expertise that they need.

I totally take Stan Wright's point about the young person I spoke about earlier. We do not see the other side of the service. Given the clinicians' circumstances, they might not have known that that young person was coming to their clinic. My challenge back to them is that that is not that young person's issue. We need to think that it is our issue—irrespective of whether we are working with the NHS, social care or another service. The young person should never have to see what is going on behind the scenes to make things work for them. If the system fails for them, we have to step in and examine the situation.

If the issue is one of supporting better information technology or better communication—whatever structure needs to be put in place—we have to consider putting that in place, otherwise young people might disengage from a service. If a young person comes away thinking, "I'm done with that now," we have lost that person from the service.

Margaret Kelman: Jane-Claire Judson has just spoken about disengagement, which is one of the points that I was going to raise. There is indeed an issue around the disengagement of young people. They get to an age when they start to think that they might not need the service any more—whether or not they actually need it.

We have been talking about responsible people and co-ordinators. Is there evidence to show that co-ordinators have helped people to stay in the system, receiving care? There is an issue about people who disengage from the service and then come back when they have a crisis, when they need emergency care or—years later—when they want to look after their health. Is there evidence to show that involving a responsible person actually helps to keep people engaged with the service?

The Convener: Is there any good practice going on anywhere? [*Laughter*.] We have heard about Highland and one person in Glasgow, who has retired. Were things any better when that poor person was trying to deal with all this? What was his job? Was it to inform other people in education and training who were dealing with young people, or was the person the gatekeeper? Was he expected to solve every problem that came to him? It seems to me to be a bit of a stretch for one person in the biggest health board in Scotland to change the culture that we have all spoken about.

Dagmar Kerr: I would like to answer that question.

The Convener: Go on.

Dagmar Kerr: That person developed a transition policy and a young people policy. If someone does not get an opportunity to implement things and the post disappears because of budget restraints, there is no way of providing evidence. The opportunity would have existed for that person to say of the policy, "Here is something that we can use to start training within the service."

We have one-off pockets of evidence. When a problem arose in an adult ward, the young people co-ordinator delivered on-the-spot training for the team that had problems so services improved, but that is not enough to provide evidence in the way that Scottish intercollegiate guidelines network guidelines would want it. If a person does not get a chance to produce evidence, I do not know where we can start. We have been trying for so long.

The Convener: Yes, I understand. I took time to read the submissions, in which there are many ideas and problems. Are there national guidelines or protocols for dealing with young people? If so, why are they not being followed? As I said earlier, we are not short of policy from the work that has been done. Why are the boards not following the guidelines and the policy that the Scottish Government has encouraged through various initiatives and, indeed, through subsequent legislation that offers a greater opportunity through the named person and the integration of health and social care?

Dr Simpson: May I ask a small supplementary question?

The Convener: Yes.

Dr Simpson: We have NHS National Services Scotland, within which we have the beginnings of a regulatory regime, and we have the joint improvement team. Are any of the people around the table even vaguely aware of an inspection of transition services having occurred? Has there been any regulatory intervention?

The one thing that NSS has to do is pick up good practice, such as in the Highland example that was mentioned, and say that it has found a way that has worked. That way may not work for every board—because of the size of the board or its geography—but it might be worth trying, so the central body should encourage boards in that. Equally, if the boards do not do what is suggested and they are hearing concerns and getting complaints, they can say that the new system is not about making complaints—as in the Patient Rights (Scotland) Act 2011—but about expressing concerns and comments and involving patients. Is anyone aware of NSS playing any role in any of that? If it is not, that will be a disgrace; it will be shocking.

The Convener: Richard Simpson has answered his own question.

Dr Simpson: No, I have not.

The Convener: We can come back to that.

Dawn Crosby: Dr Simpson is asking why the policy is not working. I think that it is because policy has been written in either a paediatric or an adult context. The better cancer care plan starts at the age of 18, and there is a cancer plan for children and young people, but it is a cancer plan—it is not a plan for children and young people. We have discussions about the lack of engagement by both sides: I keep saying "both sides".

The Convener: I read in the papers that some of the work that has been done on cancer is being rolled out more widely. Did I misread that?

Dawn Crosby: No. I can talk only about the cancer sphere. At the very least, there are pockets of good practice. In Glasgow, for instance, there is the transition clinic, and in neuro-oncology in Edinburgh, people are starting to use its principles and are transferring them elsewhere.

The problem with transition is that there are separate hospitals; there are adult hospitals and children's hospitals, so there is a physical barrier as well as a policy barrier. There is no seeing a person through the system in a way that cuts across from paediatric into adult services, which is why the policies are not working.

Scott Read: Silos have always been the biggest issue in transitions. We are sitting around this table talking about health policy; I know that Education Scotland inspects schools on their transitions and on getting it right for every child, but does that happen in healthcare? I cannot answer that, because I am not sure. However, silos are a nightmare, as are cross-resources, so it is about people looking more widely.

We have an opportunity in respect of the idea of focusing on young people's or children's outcomes within social care, based on the Social Care (Self-directed Support) (Scotland) Act 2013. It is no longer about comorbidity or other such medical labels but about what we can do to ensure that the young person's outcomes are met. That might be a healthcare consideration, a social care consideration, a third sector consideration, a college consideration, a housing consideration or a Department for Work and Pensions consideration. However, it is about focusing on the outcomes.

The focus on young people's outcomes within social care is the one policy that should cut through all the silos of different legislation and policy in order to try to solve the problem. One of the challenges for the transitions forum is that there is very little cross-committee focus on what is happening in transitions within other areas, which would help it to pull things together across the silos in order to solve problems in terms of "getting it right in healthcare". I am trying to avoid referring to getting it right for every child.

Colin Young: We can blur the boundaries between policies as much as we want and we can say that the transition starts at 12 and that everyone should work happily together on it. I have tried having that discussion, but as soon as we get down to money and who spends the money on securing the services, it falls down; the age-old argument about whether it is a healthcare path or a social care path still goes on. Young people who are moving on to independent living are not getting the care that they need because we do not want to spend the money on them, so we punt social care to local authorities and keep health national purely so that we can maintain a bun-fight between both sets of agencies. If we got rid of that distinction, it would not matter where the money to pay for anything came from.

If we look at social care, self-directed support is purely funded through the Social Work (Scotland) Act 1968, so for that reason the NHS thinks that it has nothing to do with it. Until we bring healthcare into that sphere of budgetary consideration, there will be no joined-up approach.

Jean Davies: We have some opportunities and there are frameworks already in place including, for example, joint improvement teams, co-production models and quality collaboratives, into which a lot of energy and resources are being ploughed. We are, at the moment, concentrating specifically on the early years but, as has been said, the transitions are across the whole life course of a person.

We already have collaboratives 1, 2 and 3. We are moving towards children who are older and are becoming young people, but if we could get some momentum with the later ages and stages within the quality collaborative, I think that there would then be a mandate through an integrated approach in which everyone was working together and coming up with results.

10:45

I will just make another point. A few years ago, when we did not know what would happen if a child in the Highlands or the Borders collapsed and became critically ill, the emergency care framework was developed with high level outcomes and local outcomes. Each board was tasked with time limits to produce the goods; those goods have been produced and lives have been saved. We need to take that radical approach, fit it into a care collaborative and use some of the lessons that we have learned from patient safety about short, sharp communication using SBAR—situation, background, assessment, recommendations—which is one sheet of information. That could be sent to the clinic before a child arrives by the person who is transitioning the child from paediatric services. It could be attached to the young person's notes. We already have tools in our toolbox, so why are we not using them?

Dr Wright: I will go back to the point about an evidence base. I am not an expert, but in reading around the issues before I came here, I did not find an awful lot of evidence. However, the lack of evidence should not hold us back. There are a lot of good ideas; the problem is in getting them into practice.

Our health board has tried to put together a multidisciplinary team through which the adolescent is referred to a nurse, who tries to get all the information. There are neurologists, respiratory teams, and various other medical teams, as well as social teams, which should discuss the patient to establish how they will transition their care. However, that has not really happened. It comes down to what Colin Young was saying; there is a lack of resources and we need time. Such measures require a big time commitment, and an out-patient clinic is not the place to do it.

The Government and the NHS need to develop the standards and to say what is expected. They might not be the right standards initially—we have learned that from cancer care, where we started off with standards and ended up with quality performance indicators. There has also to be some way of monitoring that because our system is not working, although no one is shouting at us and saying, “This isn’t working; what are you doing about it?” Someone has to look at the system, say why it is not working, and say what the problems are.

We need to get back to Scott Read’s point. Once we have standards, we can look at the outcomes of those standards. We can speak to people who are going through the system and ask them what they think, and we can then try to improve the system. However, at the moment, because we have no standards and we have no system, we do not know what to measure.

The Convener: The committee will discuss this meeting and decide what to do with the information. We could simply pass on the *Official Report* of the meeting to the Government, or we might want to write to health boards or put specific concerns to the minister. That is why I am encouraging people to focus on the gaps. Can we make even the slightest difference with this one committee meeting? That is what we are trying to do.

Dagmar Kerr: We are looking for evidence, and there are some models that we could probably translate. The GIRFEC model has been cited a lot, and there is also the person-centred approach that is being rolled out across the NHS, and which focuses mainly on the elderly.

Efforts are being made for very young people and for much older people. I do not see a huge difference between the person-centred care approach and the GIRFEC approach. If we are going to look at the person and what that person needs, it will be exactly the same for adolescents. In November, Action for Sick Children is having a conference at which we will ask whether there is person-centred care for young people, who seem somehow to have fallen through the mesh.

Margaret Kelman: If you are looking for evidence, a lot of the national managed clinical networks have been developing recommendations. We are not able to enforce standards, but we can develop recommendations and we have been doing that with paediatric allergy, in terms of considering what is the most suitable way of developing a transition pathway. Because one transition pathway will not fit all conditions, a good port of call would be the national managed clinical networks, a lot of which are disease or condition specific and have looked at individual cases.

Pathways need to be flexible and need to be built around the person, which is what the national managed clinical networks are good at doing. We are good at taking into account the patient perspective and the healthcare perspective and looking at the service to see what best to recommend in transition, but we need support to implement those recommendations, because we do not have the clout to make it happen. We need something in legislation to tell us the way forward and what we should be doing for specific conditions. That would be a good support.

Dr Abu-Arafeh: You asked why a good process of transition is not happening, convener. It is an interesting question, because we are all frustrated by the fact that it is not happening. Ten years ago, my service started a neurodisability transition clinic for children who were turning 15 or 16, but I could not maintain it and I am sad that it has fallen by the wayside. The reason why that happened is that, for most health boards, transition is not a priority. They have lots of targets to achieve but there are lots of restraints on resources and funding.

I started a transition process in my health board area because there were more priorities. The target of 12 weeks between new referral and treatment has become more important for the health board, and they want me to focus my attention on that, whereas transition requires a planned clinic, which is time consuming and must involve three or four people being in one place at one time and seeing only two or three patients in one morning. A lot of people see that as not being cost-effective, compared with seeing 10 or 12 new patients in one session and clearing the waiting time.

If we want to take something from this meeting, and ask the Health and Sport Committee to do something good for children of transition age, we must promote the importance of transition—as I hope we have already done. We must convince the Government to make it a priority for all health boards to look seriously at the matter and to provide the resources that will be required for the standard of transition that we are trying to achieve. Otherwise, it becomes fragmented and there will be different standards for different health boards and different conditions.

The process also needs to be monitored and health boards have to be held to account if they have not, 24 months after committing to produce a transition process, done so. If they do not feel that they are under pressure or are being monitored, it will probably drag on for another 20 years.

The Convener: It might be the wrong question to ask, but how many young people are we talking about?

Dr Abu-Arafeh: Between 2 and 5 per cent of all children have chronic diseases, and in Scotland 20 per cent of our population are children. We have 1 million children under the age of 18, so 2 per cent of that would be about 20,000 children.

Scott Read: Can I clarify something about your question, convener. When you asked whether there was evidence, what evidence were you looking for?

The Convener: I was referring to the papers. There seems to be a lot of policy and evidence that indicates, as Dr Abu-Arafeh pointed out, that transition is an issue that can not only impact on the individual but can increase risks to health and costs to the health service. I was asking why there was no effective co-ordinated action on the existing evidence and policy.

Scott Read: There are rafts and rafts of evidence and data. Some pretty new data have come from the "supporting health transitions for young people with life-limiting conditions: researching evidence of positive practice"—or STEPP—research project, in which Together for Short Lives is involved.

The Convener: It seems from the written submissions and the evidence that we have heard that we are not using the evidence to good effect, because people are not getting the result that they would want. All the witnesses have expressed a level of dissatisfaction. There is lots of evidence and there are lots of submissions and ideas, so why are they not affecting the situation, which it was said earlier has not changed in 25 years?

Scott Read: I would probably say 38 years.

Sheena Dunsmore: I will quote two of the children from whom I received a response. One said:

> "At the children's hospital, they were lovely. They did a lot to make sure I was comfortable. However, once I was with the adults, I was left to my own devices. I didn't speak to any of the other patients or get any support from the team of doctors or nurses. Once I left the children's hospital, that was pretty much it. I did not correspond with anyone unless I contacted them first. It didn't bother me as I was confident enough, but other people would have a problem."

Another child said:

> "When making the transition from paediatric care to adult care, at first I was very scared and didn't want to move into adult care as I had been looked after so well all my life. However, with the involvement of the paediatric and adult teams within the renal departments, the move over was very smooth and every person involved was very supportive and provided a great amount of advice, along with an understanding of how big a jump it was going to be into adult care."

That is how every child should feel. That was one of the very few positive responses I got; they were mostly negative.

Richard Lyle: I refer members to my entry in the register of interests and declare an interest as an unpaid member of the board of Phew (Scotland) in Motherwell, which provides respite care.

I note what has just been said. One lady contacted me to say:

> "In the children's service my son received good support, but when he went into adult services he was dropped like a hot potato. He lost his befriending. His respite was cut in half. He used to get regular health reviews when he was at school by the paediatrician, but that stopped as soon as he finished school. I took him to the GP and asked for a review, but they told me only to bring him if he was ill."

That concerns me.

Given all the evidence that has been presented, why do we not plan ahead? Local agencies must know that teenagers are going from education to adult services in the same council area and the same NHS area, so why are we not planning ahead for those children coming out of one situation and going into another?

Dagmar Kerr: Because they are different budgets.

Jean Davies: Sometimes it is not the same health board area. In a health board such as mine, in the south-west of Scotland, care for a young person who is fully ventilated would not be provided by their local clinicians in NHS Ayrshire and Arran but by clinicians in the Southern general hospital. That is an added complication in transfers that are already difficult and has to be brought into the equation.

11:00

Dr Wright: That is why we need to have local care that transfers easily into centralised care. In the example that has just been given, the service is very specialised and clinicians in NHS Ayrshire and Arran will not be experts in it. Things can go wrong on a Saturday night, so the hospital has to know that when the patient arrives at hospital, such-and-such a person has to be contacted. We need to develop those pathways.

As Ishaq Abu-Arafeh said, an awful lot of transitions go on among patients with diabetes and suchlike. Those patients do not have the same problems as those who receive complex care, who unfortunately have an awful lot of problems. We cannot look at the issue and say that we will set up a system in each health board. We have to set up a system around Scotland, so that people have local access no matter whether they are in the Highlands or the middle of central Scotland and can plug into the different services and get that expert knowledge. No one person can provide all the knowledge these days—it is not possible. Communication and co-ordination will be so important.

It does not seem to work at the moment, although it has worked. There is much better working in cancer care, with a regional group looking at what can be delivered locally and what can be done regionally. Maybe we need to look at that as well.

Scott Read: One of the things that the Scottish Transitions Forum looks at is local transitions forums in local authority areas. The issue is as basic as getting together in a room people from paediatric care, adult care, the third sector, opportunities for all and all the raft of policies, to ask what can we do together to improve the situation in which we find ourselves. That is off the back of the idea of co-ordination.

Dr Abu-Arafeh: Mr Lyle gave a very interesting example of parents feeling that their child had been dropped like a hot potato in the transition from paediatrics to other services. This is about managing expectations. It is very unlikely that we will be able in the foreseeable future to replicate paediatric services in other services. That is not happening because we do not have the equivalent of a general paediatrician looking after a child, with a general physician looking after an adult—or a young man or woman.

The process of transition should acknowledge that there will be a change in services’ approach and in how services are delivered. Children need to be prepared for that change and need to take part in it, and parents have to know what will happen next year or in a couple of years. When there is joint consultation with paediatricians and others over a period, expectations can be managed and clarified so that people do not get nasty surprises, as they did in the example that Richard Lyle gave.

We have to be realistic: we are not going to provide adults with services like those we provide in school health or paediatric clinics. They have to be different, but they must be effective and safe and they must meet the needs of the child or adult.

Scott Read: If we are looking at personalised care for children and young people as they become adults, why do they need to fit into a system? Why does the system not fit around them? Instead of the young person going into adult care and finding everything different, we should look at what that young person needs and how the system can fit around them.

Dr Abu-Arafeh: There is no equivalent in other services to what is provided in paediatrics. We have to meet in the middle and accept that services might look different, although, as you have said, they should meet the needs of the child or adult. There is no escape from that.

Dr Simpson: No one has mentioned primary care. Leaving aside complex cases, which clearly need a highly specialised, managed care network that engages local health boards with central health boards, if appropriate, adult services for conditions such as diabetes and asthma are predominately run by primary care. Where does primary care fit into all this, given some of the new concepts, such as networked primary care?

We are not talking about individual practices now; if the college’s view is followed, there will be groups of local healthcare co-operatives and groups of practices working together, such as we had in the 1990s, providing a combined service. People might not get a service from their own practice; they might get it from somebody co-ordinating care across practices. Is anyone aware of any models in that regard that would apply or that could give us some lessons?

Dr Abu-Arafeh: Yes. The patients with epilepsy whom I see have a chronic disease—a lifelong condition. They fall into three categories. One category is those who are very well controlled; they do not need treatment and they only need monitoring and advice. GPs and primary care workers seem comfortable with looking after kids in that situation, as they grow into adults. They will be seen in general practice.

Sometimes, however, GPs feel uncomfortable looking after children with such conditions. All their lives, some kids might have been looked after in secondary care or in hospital, and suddenly, they move to general practice. That is a transition in itself, which has to be managed. It has to be explained both ways. GPs have to be able to provide comfort and support in looking after those kids, and the parents, too, should feel able to trust the GP. The previous year, the GP might have been refusing to make any changes in medication; but now, because the patient has turned 16, the GP takes on full responsibility for them. That is a very interesting situation. As has been mentioned, primary care can take on a huge amount of responsibility and do a huge amount of work for these kids.

Dr Wright: We have to re-engage with primary care, as we mentioned in our short submission. Because of the holistic nature of paediatric care and because of what Ishaq Abu-Arafeh has been describing, paediatricians tend to take over all the care, especially in complex cases. When there is a problem, general practitioners will phone up Yorkhill or Edinburgh and bypass the services. The GPs get more deskilled and less confident, and will refer patients straight back to the secondary services.

We have to find a way of re-engaging the general practitioner when patients reach adulthood. It would be very nice if the general practitioner was that responsible person—responsible for the patient's care and for bringing in the other services. That would require education of the GP, so that they are confident to do that, and secondary care services that can respond right away when there is a problem.

Dr Simpson: There is a group of GPs with a special interest—that is very strong in Scotland. They are not in every practice, but they are there. There are also nurses with a special interest within practices. They might be general community nurses, but they have many sessions at which they act as specialists. There is great potential there for the sort of holistic care that Scott Read was talking about. Nurses in particular should have the capacity to go well beyond medical care and medicalisation; they can actually help in demedicalising, as well as with social care.

Dagmar Kerr: There is a great opportunity to get more involved with general practitioners. One of the problems is the IT infrastructure. Hospital computers might not be able to engage directly with GP systems, or GPs might not be able to look up all the necessary notes. It is soul destroying to take somebody with complex needs to a GP who does not know how to access all the notes that they need.

Scott Read: I have a good example of a GP thinking outside the box and holistically with regard to what is called social prescribing. If somebody has a fall, for instance, they would normally have a hospital admission, but the GP socially prescribes a sitting service or a support service to support the person in their house. That prevents the hospital admission, which prevents the spend that goes along with that. As has been said, GPs have opportunities to think creatively about such cases, and about how that approach could tie into transitions.

Colin Young: Sir Ian Kennedy's review of health services for children showed that the parents of disabled children are more likely to go straight to accident and emergency rather than to GP services, because of the critical nature of the condition and the fact that a lot of hospitals will have the experience of working with the child from repeated admissions. GPs will not have the same frequency of contact.

Picking up on the IT problem, information needs to follow the person rather than the system. A lot of work has been done on hospital passports, whereby young people have a basic booklet with everything in it that they find important about their healthcare needs, so that whoever they come into contact with knows instantly what support they need to achieve their health outcomes. That is a simple, practical solution, which could be implemented more widely.

The Convener: A good example of the issues around transition was given. There should be opportunities for those who will be responsible for picking up the care to have contact with the families and the individual. Otherwise, the GP who will eventually pick up that care will not be part of the process until he absolutely needs to be. The IT issue is another example.

However, there is some positive news. Last week, I visited a new special needs school—Craigmarloch—in Port Glasgow. I was interested to note that the school meets a wide range of needs. It was pointed out when we passed one office that that was where the children's nurseries and the health service were located and that another one was where social care services were located. I highlight that as an example of good practice, which offers hope. Such models are based around education but integrate social care aspects and the children's nurseries and make them accessible, which is important given that those services will be a constant in the family's life for a very long time. There are good models out there and it was nice to see that school last week.

Jane-Claire Judson: On the question about primary care, for children who have type 1 diabetes the diagnosis can be quite traumatic. That is partly because GPs are unsure of the signs and symptoms of type 1 diabetes and do not get the diagnosis done in a very positive way for the child or their family. We hear stories of children being sent away over the weekend to come back on a Monday morning, by which time they have already been admitted to A and E in diabetic ketoacidosis—DKA—or are slipping into a diabetic coma.

There is a problem if, at the very start of the journey, primary care is not enabled to identify type 1 diabetes—although NHS Scotland will roll out a campaign on that to primary care to raise awareness of the signs and symptoms of type 1, which is brilliant. Type 1 diabetes is dealt with in secondary care, because it is such a specialist area and parents really want to be able to trust the service. However, there is a question about how parents feel about going back into primary care at any time for something that is not directly related to the child’s type 1 but which could affect their diabetes. The child might have a cold or their parent might think that they have the measles, but they are much more likely to pick up the phone to the paediatric diabetes specialist nurse than they are to phone the GP.

At the stage of diagnosis, children pretty much go into secondary care. Given that the diagnosis might not have been a positive experience, the family might not want them to go back into primary care and I question how we would support people to do that. Once someone who is type 1 becomes what we consider to be an adult, the transition process has to include primary care and how a person feels about accessing their GP as opposed to a secondary care service. We would want them to go to their GP for certain things, but the issue is whether they would feel comfortable doing that if most of their contact with the NHS until then has been with paediatric secondary care services.

11:15

That probably feeds into the holistic idea. We have talked about the difference between paediatric and adult secondary care, but primary care is also essentially and in many ways an adult service. We need to look at why we do not take a holistic approach to what we call adult services. In some ways, GPs are best placed to take that holistic approach by bringing in local services and making connections.

I have a good example from the diabetes area. A children and adolescent working group for diabetes has been set up to look at how transition is working. It occurs to me—I put my hand up, because I sit on that group—that we do not have primary care input into that group in any shape or form. Whether we should have such input is a big question; many people would argue that we need very special secondary care for people with type 1 diabetes, whether they are in paediatric or adult care, but there is a question around how we set up the barriers, how we see the NHS, and how we should break that down.

The convener talked about how we can set transition standards and make policy, but how will that policy be delivered? A good example of co-ordination is that when we set the insulin pump targets in Scotland, a named individual in each health board was responsible for delivering that service. That individual might not have been the nurse who was delivering the service directly to a patient, but in each health board we knew who would be managing and reporting on the service, and that gave us absolute transparency and massive accountability.

As Dagmar Kerr said, there is a real need for us to look at the levers in the NHS that ensure that, if we introduce a transitions policy or standard, we know who is to be held accountable and who we can contact to ask how it is going and how we can help.

The Convener: Does each health board have a transitions policy?

Dagmar Kerr: No.

The Convener: Well, there you go; before we get the person, we need the policy.

Bob Doris: We are coming full circle with some of the conversations. Richard Simpson mentioned what the Government and NSS inspects and monitors. One of the things that has changed recently is new national care standards and the idea of joint assessment tools for health and social care. The committee has often spoken about assessing the care pathway and capturing some of the individual experiences of when a service is being assessed. Hopefully, we will contact the Government and ask whether it will capture each time a cohort of people who are of an age to have been through significant transitions from youth to adult services, and whether it will embed a routine inspection process for that.

Is anyone aware of the good work that is being done just now? Have you heard talk about it, or are you aware of any such inspection taking place with a deliberately identified cohort? If you are going into a hospital to look at a service, by definition any cohort of young people there will have been through a series of transitions, some of which could be captured during a routine inspection process. It might not always be a matter of doing a catch-all inspection of transition services because that might not get the information that we need, which is individual experiences informing the inspectorate when it is assessing. Have you been involved in anything like that, or is it on your radar?

Yvonne Hughes: The Cystic Fibrosis Trust carries out peer review, which would include transition and provide data. That is the only thing we have that would match up with what you suggest.

Bob Doris: I threw the idea out there because there could be an opportunity to catch data in the near future, depending on how adult services are assessed and whether they identify a cohort of people who are most likely to have been through such transition. Some of that could be inspected with the new national standards.

The Convener: Bob Doris is raising the right questions and trying to establish what is going on out there and to identify some of the gaps. The committee has received many good written submissions, and given the interest in the issue, we have had a good meeting this morning.

Rhoda Grant: There seems to be a degree of agreement that when someone is coming out of children's services into adult services, the GP should take on the role of the paediatrician. That should create a seamless service at that time.

People have told horror stories about young people's experiences. It seems to me that anyone who enters a service for the first time and is dealt with in such a way would have a really bad experience, because they are basically dismissed. If we are serious about having good-quality healthcare, surely anyone who meets a patient for the first time should treat them with respect and consider how they will deliver the service to them in the way that they would want it to be delivered. Not answering questions in the way that someone would want is wrong on every level.

If the GP, for example, was more involved in that, that would create challenges in itself. How often does someone see the same GP, as they would see the same paediatrician, in order to build up that kind of relationship? That is a challenge on its own. Is that what people are thinking, or do we need something that follows through? If we are saying that older people and young people need a key person in their care, are we missing out a raft of people, especially those who have complex care needs and perhaps use not one service but several services?

Sheena Dunsmore: Many children with whom we deal have probably not seen their GP for years. They deal with the children's hospital. That is where they would go if anything was wrong with them. The GP would therefore be as much a stranger to them as the adult services are.

Dr Abu-Arafeh: Most of the kids whom we are talking about require specialist services, whether from paediatricians or physicians. Unlike our neighbours in continental Europe and North America, we do not have primary care paediatric specialists in the United Kingdom.

Richard Simpson talked about GPs with a special interest. That model could be progressed in the future. The GP can take interest in certain conditions or a certain group of children, develop services for them and become the key person to monitor those children for the rest of their lives. A GP can be interested in paediatrics, respiratory conditions or neurology. That model works very well in continental Europe and North America, but we have never had it in Britain.

I do not have a solution to that, and I do not think that the situation will change in the near future. However, it would be an ideal situation if we can develop the concept of GPs with a special interest and consider specialists in primary care.

Dr Wright: The example was given of a patient who turned up at the adult clinic and had never been seen there before. The clinic did not know anything about him, and he knew nothing about it. We can put in fancy arrangements, but solving that issue is pretty basic. The adult clinic can make contact with them beforehand. It could be said, "I am Dr Wright and I will be looking after you" and so on.

We cannot get round the fact that the adult services differ from the paediatric services. I hear what Scott Read says, but they are different. I do not have my head in the sand. We have to adapt to suit people's needs, but we cannot often provide for all their needs. That is not possible in the service. There are boundaries and resource issues, and we cannot do everything, but we can certainly make the transition much easier, and communication is a big part of that. However, getting the adult physician or surgeon to go down to a paediatric clinic means time. It means that they have to free up a day, get a time when everyone can meet, go and meet them, read the notes and make contact; they might even have to do that several times, depending on the complexity of the patient. The patient then has to come to the adult service, and perhaps the paediatrician will come to the adult service as well for the first time. That requires a resource, and there is no easy way around that.

Dawn Crosby: I want to pick up a point—actually, I have a question. We are talking about the transition from paediatric to adult services, but there is also a transition when someone becomes a patient for the first time and comes to a clinic for the first time. Is there any difference between someone going to an adult clinic for the first time and someone who is transitioning from paediatric services? Surely, there should be an induction. As a brand new patient, I would expect information on how to get to the clinic and what I can expect when I get there. Surely the same principles apply, or is there an assumption that, because somebody has been in the system for a certain length of time, they should know what to expect in transitioning to adult services? Actually, I think that they are a new patient all over again, so they need something like an induction.

Sorry, convener, but I will nab this opportunity to make another point.

The Convener: Go on.

Dawn Crosby: You asked why things are not happening, convener. I would want to ask the health boards that. Given that there are policies across all paediatric services, I want the

Parliament to ask the health boards why things are not happening, or why those policies are failing.

Dr Abu-Arafeh: Dawn Crosby asked a question about patients going to hospital for the first time. As I mentioned, the issue is to do with expectations. The problem is that patients in paediatrics have certain expectations and they think that those expectations will continue to be met. If we do not give people the proper induction and inform them that things are going to change, they will get the shock of their lives. As Stan Wright says, it will be different. We have to accept the differences between the two types of service, but we have to manage those differences and expectations and make the transition smoother. Why are things not happening? As I said, the issue is not a priority for most health boards. It costs money and takes effort, and they have other targets to achieve.

Jane-Claire Judson: Dawn Crosby made a point about new patients. For many young people with type 1 diabetes, when they transfer to adult services, they realise that in fact their parents held a lot of the information about the risks and complications of diabetes, such as foot disease and retinopathy, and that they do not know about those things. Dawn Crosby is absolutely right about that.

We have talked about the differences between paediatric and adult services. During the meeting, in my head, I have been drawing a parallel with education. We do not expect tertiary education to be the same as primary education, but we still expect students to have a holistic experience while they are at university or college. Services are put in place to ensure that that happens, whether someone is going to further education at 17 or going back as a mature student. So, there are ways to do that. We should look at that and ensure that adult services try to build in a holistic approach. I totally accept the challenges, but I think that we should try to meet them.

Scott Read: We need to remember that it is not just a health transition that is happening, although I know that we are here to talk about health transitions. We have situations in which an adult social worker cannot come to a meeting. They have a risk-based case load, so why would they go to a transitions meeting in one place when someone is in danger of dying somewhere else? There is a draw on them from elsewhere, and I guess that the same applies in adult health and paediatrics.

We should keep hold of the idea that a lot is happening for young people during that period, and that transferring to another clinic might not be their biggest priority. They might be thinking, “I really fancy that girl in my class and I’m not going to see her again.” A raft of things are going on. Whatever happens, we should ensure that it is done with a foot in social care and a foot in education, and that we try to pull all that together and see how it can best fit together.

The Convener: We do not know what opportunities lie in the integration measures and in recent legislation such as the Children and Young People (Scotland) Bill—we have guidelines to come on that. However, I would have thought that some basic rules of engagement, consistently applied across the health boards, would at least be a help.

I thank all our witnesses for their written evidence and for giving up their precious time to be with us this morning. We will discuss the committee’s approach to the issue. If you feel that there are points that you could or should have made—on the way home, people sometimes think of something that they wish they had said—let us know. You can do that informally; just contact the clerks to the committee.

11:30

Meeting suspended.

11:39

On resuming—

Petitions

Non-residential Services (Local Authority Charges) (PE1466)

The Convener: Agenda item 4 is consideration of three petitions. I will take the petitions in the order set out in paper 7.

The first petition is PE1466, on local authority charges for non-residential services. Members will see from the arguments in the paper on the petition that there is little or nothing further that the committee can do on it. The suggestion is that we agree to close the petition but draw it to the attention of the Local Government and Regeneration Committee for information. Do members have any comments? Richard?

Dr Simpson: I am sorry, convener: I am back interrupting you and holding things up. [*Laughter*.]

Richard Lyle: And you are quite welcome, too.

Dr Simpson: The very welcome thing is that the Convention of Scottish Local Authorities is now publishing the charges. I know from personal experience that that is already having a political effect. If when local authorities are drawing up their budgets their charges are below the average, they are tending to limit increases to putting them up to the average. Of course, that moves the average up, but nevertheless it is a reasonable constraint, and those who charge above the average might in turn be constrained not to put up their charges. I think that that is very useful.

The letter from COSLA in March 2013 referred to “a fundamental review” of charging policy. Do we know whether that review has been completed? Has the petitioner been advised as to whether it has been completed? Should we advise the Local Government and Regeneration Committee that it might wish to take that matter up with COSLA instead of this committee doing so?

The Convener: We could certainly also draw the Local Government and Regeneration Committee’s attention to that point, but it is not for us to decide that committee’s work programme. We would pass on the petition and make the point.

Bob Doris: I concur with what Richard Simpson said earlier: yes indeed you are back and it is good to have you back, sir.

I remember the previous evidence session on this petition. There seemed to be a bit of nervousness about publishing the various charges that each local authority levies. I think that I suggested that perhaps the local authorities should inform their constituents where they ranked out of the 32 local authorities so that they could see whether, for example, they were the most expensive in the country for having grass cut or the least or most expensive for bulk uplift.

It is good that the authorities are now systematically publishing such information, which I think in itself has been a bit of a result for the petitioner and this committee. Dr Simpson’s comments reminded me of that, and I want to stress it for the record.

The Convener: Do we concur with the suggestion, then, that we close the petition but draw it to the attention of the Local Government and Regeneration Committee for information, with the addition of the point that Dr Simpson made?

Members *indicated agreement.*

Respite Services (Young Disabled Adults) (PE1499)

The Convener: PE1499 is on creating suitable respite services for young disabled adults with life-limiting conditions. Members will see that the paper on the petition suggests that we consider the petition as part of our consideration of the work that we did earlier this morning on transitions between paediatric and adult care. We could include discussion of the petition in our normal private consideration of earlier evidence, but we did not address many of the petition’s issues in the earlier session, so we need to decide how to address them.

Bob Doris: Having looked at the petition, I think that, again, it is unclear what role the Scottish Government should play on the issue compared with local authorities or, indeed, health authorities. We have just passed the Public Bodies (Joint Working) (Scotland) Bill with regard to health and social care integration. I agree with the convener that we did not really mop up much evidence on that in the earlier evidence session.

We need to decide what action to take in relation to the evidence session that we have just had, and we should probably have discussed this petition after we had decided what to do in relation to the round-table discussion. However, I would be content to consider the petition as part of the action points from the round-table discussion and specifically mention it in any correspondence that we enter into. The way that the agenda has worked out has perhaps put the cart before the horse, but I would be content to agree to consider the petition as suggested, as long as we specifically refer to it in any correspondence on the round-table evidence.

11:45

Rhoda Grant: We did not really cover the issues in the petition in the round-table session. We were not focusing on acute health service for the most part.

The petition also takes in things such as education. A lot of young people with special needs who are in children's services are also in education. They go out every day and respite is built into that—there is a whole-family approach. However, the minute they hit 18, education services pull back and, as someone mentioned during the round-table session, those people suddenly find themselves at home 24/7 with a carer whose life might be turned upside down—they might have to give up work because the services are no longer there.

There has to be, somewhere more centrally, a look at how we provide services for people, especially respite for young adults. I have seen people consider care homes for respite for young adults, which is totally inappropriate. We must also look at how we provide an on-going package, recognising that it is the same for some families as it would be if they had a dependent child. The person will not become independent, so we need to view them and how we put support in place quite differently.

A number of my constituents are very concerned about the issue. As we get better at looking after people and as people with chronic conditions live longer—which is a good thing—we have to look at how we cater for them into the future.

The Convener: The issue for us is how we give the petition due consideration. Bob Doris suggested considering it alongside evidence from this morning's session. At that point we might decide that the petition does not fit with the committee's consideration of transition and that it needs to be dealt with separately. We might have to consider whether we should take evidence from the petitioner or, in the first instance, write to the Government to ask it to clarify its response. Should we make a decision about that today or when we consider the aspects of young people's transition and the wider services that are provided for them?

The petition deals with a transition—services are in place until people reach a specific age—so in that sense there is some commonality with what we discussed this morning. Could we write to the Government about the issues that were raised this morning and the petition? Would that take us forward?

Richard Lyle: I seek clarification. I referred earlier to my entry in the register of interests relating to a respite centre. Should I declare an interest in regard to this petition?

The Convener: Well, you just have.

Richard Lyle: Thank you. I do so.

Bob Doris: The petitioner will be following this process, and you mentioned a possible evidence session, convener. The petitioner knows this, but members of the public who might be following the meeting should know that there has been an evidence session at the Public Petitions Committee and that written evidence has been received from COSLA, Midlothian Council, the Scottish Partnership for Palliative Care and the Scottish Government. I am not necessarily saying that we should progress towards an evidence session, but if we do we should take cognisance of the fact that those things have already happened. That is only fair to the petitioner. I would not want them to follow today's proceedings and anticipate that there will be another evidence session.

The Convener: I appreciate that. I am not suggesting that we would choose that option, but it is one of the options that we would need to consider.

Do we agree to look again at the petition alongside our consideration of this morning's evidence?

Members *indicated agreement.*

Speech and Language Therapy (PE1384)

The Convener: PE1384 is a long-standing petition on speech and language therapy. Since we last looked at the petition, a survey of NHS boards and councils has been carried out, the details of which are in members' papers. We need to decide whether we can do much more with the petition, but before we can move towards any kind of closure it might be worth drawing the Scottish Government's attention to what the committee has done and asking it for its comments, which would give us some advice about where we should go. We could either write to the Government for its comments or invite the Minister for Public Health to give evidence.

Bob Doris: I do not see any harm in writing to the minister to get information; we should do that.

One of the suggestions was to invite the minister to give evidence on the petition. Although it has still to be confirmed, I believe that he might be coming to the committee in the months ahead. If we need to clarify any additional matters, perhaps we could ask any specific questions at that appearance. That might be a more efficient way to progress.

We should write in the first instance and, if we decide that we want to develop questions further with the minister, there appears to be an opportunity—I am looking at a private paper, so I will not say the specific details—to question him at a later date.

The Convener: That sounds sensible. Does the committee agree to write to the Scottish Government to draw its attention to the committee's work, ask for a response and say that we are considering taking some of the minister's time if necessary to discuss the petition at a future meeting?

Members *indicated agreement.*

Dr Simpson: The issue plays into the issue of integration, because speech and language therapy receives funds from both local authority and health board. I do not know who else was at the Glasgow meeting, but at it we looked at speech and language integration, which was very good. There are models.

In our letter, we should ask what working integration models National Services Scotland is looking at. Is it inspecting and monitoring what is going on? If that is not happening, is the Government looking to do it? That comes under points A and B in the list of five actions that the petitioner has asked us to consider.

The Convener: Thanks for that additional comment, Richard. We have agreed to write to the minister, with the option to speak to him on the record.

11:52

Meeting continued in private until 12:12.

Members who would like a printed copy of the *Official Report* to be forwarded to them should give notice to SPICe.

Available in e-format only. Printed Scottish Parliament documentation is published in Edinburgh by APS Group Scotland.

All documents are available on
the Scottish Parliament website at:

www.scottish.parliament.uk

For details of documents available to
order in hard copy format, please contact:
APS Scottish Parliament Publications on 0131 629 9941.

For information on the Scottish Parliament contact
Public Information on:

Telephone: 0131 348 5000
Textphone: 0800 092 7100
Email: sp.info@scottish.parliament.uk

e-format first available
ISBN 978-1-78392-872-9

Revised e-format available
ISBN 978-1-78392-889-7

Printed in Scotland by APS Group Scotland