The All-Party Parliamentary Group for Children Who Need Palliative Care

Oral evidence: how the government is meeting its commitment to choice for babies, children and young people who need palliative care

Session 4: 21 February 2018

Listen to the meeting: https://togetherforshortlives.podbean.com/e/childrens-palliative-care-voices-4-dr-linda-maynard-maria-McGill-and-toby-organisations/

Members present

Catherine McKinnell MP (Co-Chair) and Christine Jardine MP.

Witnesses

- Dr Linda Maynard (Consultant Nurse Children's Palliative Care, East Anglia's Children's Hospices)
- Maria McGill (Chief Executive, Children's Hospices Across Scotland (CHAS))
- Toby Organisations (Chief Executive, Acorns Children's Hospice).

Examination of witnesses

Catherine McKinnell MP chaired the session

Catherine McKinnell MP:

I guess we have covered quite a lot, so really we can pick up from where we left off to take this to the next stage. What really is another aspect of what really, is the other side of the same coin that we're all discussing. So, do you want to just very quickly introduce yourselves, and where you're from, and then we'll go straight into, we'll pick up on the same questions, but obviously, if it takes a whole different track, then we'll just follow that track. Wherever you want to take this discussion. So if you want to start the introductions?

Maria McGill:

Hi my name is Maria, Maria McGill. I'm Chief Executive at Children's Hospices Across Scotland, CHAS. I want to thank the committee for the opportunity to come today, and to say that, although we work in Scotland only, and we are Scotland's national hospice service, I'm in regular contact with colleagues across the UK. So for me it's really important we continue to learn from each other and if there's anything that the Scottish perspective can offer, I'm very happy to share that as well as learn from what my colleagues are doing.

Dr Linda Maynard:

Hi, hello, I'm Dr Linda Maynard. I'm a Nurse Consultant, in children's palliative care, and I am employed by East Anglia's Children's Hospices in the East of England. I'm also the lead nurse in the managed clinical Network in the East of England, and that's why I think I want to wear that hat today. Whilst the hospices in East Anglia were a key stakeholder in driving the managed clinical network, I want to be able to represent all of the professionals and organisations in the network, which includes acute hospitals, community trusts, other voluntary sector workers as-well. So, we do have a, we feel, a good system set up, but it clearly has some gaps and barriers. So if it will be helpful to share some of our learning on that over the last seven years I'd be really inclined to share them.

Toby Organisations:

I'm Toby Organisations, I'm Chief Executive at Acorns Childrens' Hospice, which is a large children's hospice charity that serves kids and families across the West Midlands. Regionally, we have three hospices in Birmingham, Walsall and Worcester, and we operate as most children's hospices do. I mean having a sort of spoke system where there are kids coming from across the region, into and accessing three or four different kinds of service, in each of the hospices.

Catherine McKinnell MP:

So I don't know if you if you are happy just to maybe give some reflections on what we've already discussed? And whether from your perspective because obviously, and you know I could ask, you know to what extent you're involved in the care plans. But I actually think we've covered an awful lot of that with the medical team that's there, so it might be useful actually for us to just pick up where we left off in terms of that interaction between health and social care, where I think sometimes you may fall somewhere between those two spokes. I don't know it would be useful to hear your insights on what you've heard discussed this morning and actually from a hospice perspective or from a community care perspective and where we might seek to improve or what's working well.

Toby Porter:

Well thank you, I mean it is, if I may say it's such an important area. It's a very difficult moment, so I think if you imagined health and social care as the sort of two circles in the Venn diagram a lot of children's hospice work lies quite squarely in the middle, but it is tough at the moment because all of the funding that we get, that's the statutory funding, is now almost exclusively from NHS sources and the social care funding. For reasons mentioned about Rainbows Hospice earlier it's just disappeared, there isn't any left and that is, that is a massive challenge. I saw a tweet yesterday, that was saying, that I think someone, in the House of Lords had made the point that the current Commission on the work on Social Care, been set up about social care, and the elderly, that the point that she was making was actually half of all social care spending in the UK goes on disabled children, and I think all of us in the children's hospice movement would welcome the political attention on social care and the need for greater integration. We'd be strongly supportive of that but what we need to say is that obviously we recognize that ageing population is a critical strategic national issue, but don't lose sight of the disabled children, that's what I would say.

Catherine McKinnell MP:

If I can ask about Scotland.

Maria McGill:

The Scottish perspective, and that we have integration of health and social care, and so these Health and Social Care Partnerships are relatively new. They're only two years old, the creation and so that does make them very young organisations, and whilst absolutely everybody understands the vision and really wants to make it work and then there are a lot of really good people trying to make that work, it's early days yet. One of the challenges that the entire third sector has is how we can engage meaningfully with health and social care partnerships, that's something that I'm trying to pay attention to and tomorrow actually I'm at an event with Sue Ryder and Marie Curie, a public event as we talk about how we can we and national organisations find ways to represent ourselves and those we serve in health and social care partnerships.

Catherine McKinnell MP:

Is it making a difference to care?

Maria McGill:

I think it's fair to say that in some places yes, and in some places not quite yet, and part of that is around funding. It's not quite the same situation as it is here in England you know money is tight for sure but I think there is, there are differences. So, integration is there and it's happening and everybody wants to make it work.

I think there's another reflection I have around we've heard a lot this morning about the importance of anticipatory care plans, and something that is UK wide and in Scotland last September, October there was a national anticipated care plan document for adults launched, and that document for children is also coming, and so, we are part of that, it's being developed by the Healthcare Improvement Scotland regulator, and one of my staff is chairing that program board. So, it's almost there, and it's based on what practitioners, the experience of practitioners, and also families. So, families have been part of that program board that will make another step forward in making sure that families and children's wishes are understood and recorded and then life can be lived.

Dr Linda Maynard:

I don't think I have anything else to add. I echo the thoughts and views. In the East of England, it's a similar picture in terms of a there's a very big willingness to engage and want to integrate, but there are significant hurdles, as the others that have been discussed. I would just echo those thoughts.

Catherine McKinnell MP:

Okay, so I'll pose a question, and actually, I should have posed this to the previous panel as well. So if you've got thoughts you can send them on a post card. What one thing would you ask the government? What one thing could they do that would improve your ability to deliver the care within your organisation? Now, it may all be the same thing or you may have different things, but it would be really interesting to understand if you had to boil it down to one thing and it can't just be money.

Dr Linda Maynard:

No actually I don't want to say money, because actually I think we've had this run over the last couple of years, through NICE. I think we have some quality standards now that we want to aspire to, we want to achieve. I think there's probably, we've had a lot of discussion around advanced care planning and that is a key quality standards in the NICE guidance and that I think for me, if there was some mandated standard by NHS England, and the health system to ensure that advanced care plans were in place, or that every child, every child who died there was evidence that there was an advanced care plan in place perhaps three months before they died. There's dilemmas and problems with that because then if you're reducing it down to a you know a time limit, or a tick box or whatever, the quality of those advanced care plans may not come through, but if you think about what an advanced care plan is all of those really important skills that we've talked about today around good communication skills listening and really valuing families in those discussions, for me the advanced care plan seems to be pivotal if you get that right, if you engage early enough with the families and it's not as necessary as palliative care teams I think Francis made that point really well but actually the palliative care is everybody's business. We see safeguarding as everybody's business, so we need to be really empowering our community colleagues our community paediatricians or our hospital paediatricians, our community nurses to acquire and have an awareness of what palliative care is for a start and then use their communication skills to put those plans in place. it's really simple, it's not difficult to do those plans but in my experience other non-palliative care professionals shy away from having those conversations because they're perceived as challenging or difficult or I don't know how to start. So, for me, I think that if there was a mandate to put that in place and that we were held accountable for that as the different providers.

Catherine McKinnell MP:

Have you got anything to add at all?

Toby Porter:

Yes I have and I would say, I would say something different and I would speak directly to the work that you're doing the potential influence that your report could have which is that we can't give you the details and you shouldn't need to know the details, but you should be reassured that all of the children's hospices are working more and more strategically with NHS partners. So we are all, the traditional thing about the voluntary sector is it works in isolation and creates these havens of tranquility if you like. Nowadays people are really trying to work very, very strategically recognizing that resources are constrained on all sides and that the financial as well as care imperatives of strategic collaboration is stronger than ever so what I think all of the major regions of the countries because I think this probably is best done regionally, must have in place are really strong plans for paediatric palliative care provision that are broad enough that they bring all of the different organisations, governmental, non-governmental to the table, and the danger at the moment as well-intentioned that they are, if everything is left to PCT's and STPs they are all operating even the STPs are operating in far too small, a geographical region to bring those plans at the moment the system seems to be well we'll just have to leave all of the commissioning arrangements to the STPs, CCGs. And some, many of them are doing valuable things but you'll never get the regional plan that is so critical. I believe your region has done this quite well?

Catherine McKinnell MP:

I didn't know that, I'll look into it. So, has that been done on a sort of a North East basis?

Toby Porter:

Yes

Catherine McKinnell MP:

Right, Ok.

Toby Porter:

I can send that along.

Catherine McKinnell:

Presumably you’ve poached the consultant in the North East because her work is done?

Toby Porter:

Well Birmingham Children’s Hospital poached her. But, Birmingham is actually one of the few regions in England that, until her arrival actually (she's not started yet she starts in April), and Birmingham would be one of the one of the very few regions left in the UK that doesn't have a specialist paediatric palliative care consultant in the hospital, and you can see that we have higher, even than high national average of stats of numbers of kids dying in hospital. So, statistics in our region or even children registered with Acorns 47% die in hospital, 23% at home, 20, whatever the bands, 24 – 25% at the hospice. It's obviously a very bad environment for the child and the family in many cases but it also is leading to struggling paediatric intensive care.

Catherine McKinnell MP:

How does that compare nationally? Do you know?
I mean it’s quite a useful statistic and obviously that's something that you're focused on as a region I didn't know if other regions were?

Dr Linda Maynard:

I think in the East the children who die at home is higher than average. I think up-to 60% or more. But I think for me the issue is not necessarily that particular stat, but it is that does that meet with the families or the child, young person's choice because there will be and there are some children and young people who choose the team around them in the hospital environment because that's the team that they know well so but I think if you don't have the right system set up to offer, I think you made that point, to offer the choice at home, so we can have the nursing team and the therapy team in the home environment, or you can go out on a 24/7 basis you don't have those systems in place then choice is quite often, is hampered, so I think the stat from the East of England would show that perhaps there is more choice because those systems are established and formalized in an informal way.

Catherine McKinnell MP:

Maria is there one thing that you would…?

Maria McGill:

So in terms of one thing it's not going to be money because again in Scotland things are a little different and in that we're in the very fortunate possession of having achieved parity of funding with adult hospices so we've had a significant increase in our funding and with that comes responsibility in terms of reaching every child in Scotland who has palliative care needs. What one thing, I think for me would be data and there are some colleagues here who might disagree with that but for us in Scotland the success we've had in terms of funding has been built on a solid foundation around data and Scottish Government to their credit funded that. We commissioned the work from University of York on numbers and needs and that actually was a game changer. It's the numbers in Scotland 15 and a half thousand children at any one point in Scotland have life shortening conditions and of those 2,200 could be considered to be unstable, to tear anything up dying, and so we absolutely understand now in Scotland that Chas as a national hospice provider understands what it needs to do to deliver those services. Now we are updating that data, cos it can’t just be a one off, and so we are very hopeful that our government colleagues and our data colleagues will produce that data annually so that it helps us plan and it needs to be used to understand where our scarce resources need to be in order to reach those families because we shouldn't expect families to come to us we should be understanding where the children are. Now we know for example, that 90 percent of under ones who die in hospitals, who die in Scotland, die in hospital, and for many of them, most of them, we believe we need to do more work, that's appropriate but what we can do is work with the teams around those babies and change the experience. Offer some choice within that environment and perhaps for some offer choice about going home and coming to a hospital but we can support the teams in those very difficult circumstances and the other bit you've asked a specific question about how did that compare nationally so we know that 90% of the children under one who die, die in hospital in terms of the rest the children up to twenty five 75% of those deaths were in hospital, 21% at home, and 5% in the hospice. Now we're not making there's no judgment on those numbers, cos it might actually be okay for a child to die in hospital and I can think of an example of a mum and dad who went through the anticipatory care planning process and talked about it being a very difficult conversation talking about the depths and the darkness of death, and, but then after it was done understanding actually now we can focus on what Jack, we think Jack would have wanted, Jack was 2 and what we wanted to achieve for Jack they also knew what they wanted to experience when Jack died and that was to die in a hospice but unfortunately Jack's condition deteriorated very suddenly just as I'd said earlier children's conditions go up and down so he died in a hospital but it was as the family described as we wanted that experience and then after he died they lifted him up and put him in the car and drove for three hours through the night to come to Rachel House and they spent the next six days with him. They said we wouldn't have known you could do that had we not undergone that process. They sang to him all the way down the road, just as they did any other time, and then we were able to support them, in that new reality.

Christine Jardine MP:

I've visited your facilities and I found it the most uplifting experience it was hugely emotional there were a few of us there and I think that we all went away changed people because we met children and parents who had made those choices and they were in this, not enviable, that's not what I mean, but they were in a position where you thought if that was me that is where I would want to be and it was because it was what they had chosen and it was a tremendous experience and I think if there is some way that every parent could experience that every parent who has to face that situation could experience that could be something to aim for because it was quite special.

Toby Porter:

Can I just add because I think it's really important, and for me children's palliative care is philosophy of care, it's not about location and it's delivering that philosophy wherever the child is. They don't need to be a hospice to receive that, they could be at home, they could be in a hospital, so it's that philosophy, and not the location, and that is so so important.

Christine Jardine MP:

Maria, correct me if I'm wrong, If I remember rightly, you also do a lot of respite care hence have the option to move in and out of what suits them, so that they are getting exactly what they've decided is best for their child.

Maria McGill:

So we would deliver the full range of palliative care, whether it's respite care, symptom management, urgent admissions for assessment or end-of-life care and we do that in our two houses. We have for at home teams across Scotland and we also have Diana nurses and the three main children's hospitals and joint appointment consultants so we are actually reaching out to where children are, and that is growing that's one of our areas of growth this year. It's not to wait for children to come to us, it’s where are they, so working with our colleagues in Glasgow we already have a neo-natal service in Edinburgh and learning from that and extending that into Glasgow, and also talking to them about a paediatric palliative care service. we're talking to colleagues in Aberdeen and Inverness about how we can deliver that there. The models need to change because of the scaling up we need to do, so our support that we deliver at home we need to change that model because if we are going to reach many more children, three times more children then actually we can't employ three times more staff we need to be able to do that differently and we can.

Dr Linda Maynard:

I think something that’s not been mentioned about that, so changing that that type of model probably means changing those that deliver that type of model so we all know that there are more nurses leaving the profession than joining we are all getting older and so the recruitment issues are common I think across not just the hospice sector but in the statutory sectors too so looking at how we can develop with our NHS partners different types of nursing role nursing associate role Assistant practitioner roles to enhance the pool of the workforce that can deliver the respite, the short break care because those children and their families need that when they're living with their conditions and they may or may not then move into needing more intensive work at end of life. But there are many now as we know from the data, more children living with their condition. So, looking at our workforce I think is another key area we can't just rely on our traditional doctors and nurses anymore we need to look at the models of how we’re delivering.

Maria McGill:

I have the responsibility of representing Scotland here. In terms work force issues, yes there are work force issues, however in Scotland we still have more nurses joining the profession than we have leaving. So, we are in a different position, the number of student places.

Christine Jardine MP:

We have our problems in Scotland as well…

Maria McGill:

But we also have an increase in the number of nurses, nursing places in university, however that takes about three years to realize those. But, there are other things we can do for example, I won’t be alone here in terms of using volunteers to support families at home directly, so a home support volunteer projects really add a richness to volunteers lives and to the lives of the community but also bring a great sense of practical support to families, having beds changed, that’s supporting, children with homework making sure their lives carry on, taking them to lessons, to after-school, and whatever else is going on in a child's life is hugely important in the palliative care experience for that family. So there are other things that we can do.

Christine Jardine MP:

Can I ask a question? One of the things which has come up several times has been money and the cuts which the service is dealing with, social work? Now, we have not been immune to that in Scotland but perhaps further down the road because of the freeze in council tax for several years. Are there things which you can identify which have happened, which you see beginning to happen in the rest of the UK, and was there a way of dealing with them?

I'm thinking you know the funding without asking towards political ground we did have an issue in Scotland with funding and we still do have an issue in Scotland with funding very similar, but I'm thinking a bit further down the line, so are there remedies that you've been able to come up with?

Maria McGill:

In terms of hospice funding persay?

Christine Jardine MP:

Yes in terms of and coping with it because we're further down the sort of social integration social care integration as-well.

Maria McGill:

So in terms of hospice funding we are in a different position, and that I think is largely due to the data and to cross-party support for the Children's Hospices Across Scotland achieving parity with adult hospice services so this year we have realized that for the first time and we saw our Statutory funding go from 1.2million to 6million.

Now that makes a significant difference to us and we are in the throes of working very closely with our health and care partnership colleagues predominantly our health colleagues to understand how we best develop services across Scotland. In terms of social care we also receive funding from Scotland's local authorities, it's a much smaller amount of money and we are in a, still in that new situation of Health and Social Care integration look for smaller charities I don't just mean hospice charities, smaller charities it's a it's easier to get engaged with Health and Social Care Partnerships they're small, they're local authority areas and they're much smaller than county areas here but from national charities like ourselves Marie Curie and Sue Ryder they're all involved in palliative care it's much more difficult hence the event that we're having tomorrow to help find solutions to that. I think there are solutions.

Dr Linda Maynard:

I think, I think, Toby's talked about the regional approach or the network approach, and I think in the East of England, we haven't solved the funding issue, we haven't really but actually by bringing the key palliative care teams together by formalizing a network of support over a much greater geographical area the economies of scale has proved effective. So, we have in the East of England just one half time so part time Specialist Palliative care consultant but there are six other paediatricians who have training dotted around the region it's not their full day job but they have negotiated with their own trusts some sessional work for palliative care.

The hospice contribution has been the specialist nursing team, and this you know some levels in that's a couple of matrons, myself so we look with that team providing care over the larger geographical area we can affect choice because the team can provide 24/7 access at home in reaching into the hospital environments to 24/7 and the medical team provide the telephone support on call all the time, so that really hasn't taken a lot of money to do that what it's taken is work to bring people together to address the governance issues around working across organizational boundaries, shared documentation and those sorts of things so it took a while to - for the organisations and the professionals to agree those governance issues but it seems to work I mean there are gaps clearly we're always learning and wanting to improve but providing a service over a larger geographical area does seem to be more cost effective and that is greater than the STP areas that are coming forward, so formalised and appropriately funded and accountable care systems over a larger geographical area.

Toby Porter:

I mean, all I would add, just agreeing with those two answers but just an obvious observation, but needs to be made, we feel glad at Acorns that we have a very committed Conservative constituency MP in Worcester where we have a hospice, we have, and then two labour MPs, so if ever we feel we need to talk about this, in a reasonable, you know without being accused… well no because if you're trying to just shine a light on the human impact of austerity it's now a difficult moment for the charity sector because that then gets equated but what I would say is that the impact of obviously the social care funding is felt by families much more than by voluntary sector organisations, and we're, I know that the councils are, the average cut to children's services for example in the councils that we work with, which is monitored, I give you a very top line view it's between about 20 and 40 percent cuts over the last five years and we're seeing families struggle and that manifests itself in lots of ways firstly because a lot of the council directly council funding, council provided services that were designed to support families as they sort of, went down into crisis as intermediary steps and services are disappearing and what we're left with is that statutory trigger whereby when things get really really bad then the councils have to intervene so you're seeing, you're still obviously seeing no change in paid for or step-down beds if there's a social care crisis or whatever because the councils have a statutory obligation to provide. What you're not really seeing is an awful lot of support to stop families sliding into crisis and it is there's no doubt that one of the challenges facing the voluntary sector is that we are seeing more and more demand on our services at a time when our own funding models are also being challenged. Most of us are finding ways around that and certainly I know EACH and Acorns and CHAS are all financially stable but is no doubt that it's creating distress and we wonder and we're also seeing referrals from kids who don't quite meet our criteria that their social worker or GP or consultant is seeing a family that isn't appropriate and there are no others and other services aren't there anymore so from their perspective illegitimate best interest of the child best interest of the family they're kind of saying well you might get lucky and go into Acorns even though your child is rather stable and doesn't quite meet the life-limiting conditions, and we're certainly seeing more children referred now.

Maria McGill:

Oh and another financial issue is for families specifically, so with changes to social security and benefit system I lost my family support team but individual family finances are really pressured and that's becoming an increasing issue for families and that's no different to any other families who use the social security system but I think it's really important that we recognize that many families with a child with a life-shortening condition that one or both of those parents will have to give up work to support the child and so instantly there's a lack of finance and so they go into a system in which they don't know and actually which doesn't adequately resource.

Christine Jardine MP:

So, would it be fair to characterize it as they're going through life-changing critical experience, and then, they have to give up work so on top of that is piled another life-changing critical experience

Maria McGill:

And might lose their house, I might not be able to sustain that. They might have to find accommodation, in another sector which might not be available. It’s just a financial inclusion power, very difficult and important.

Christine Jardine MP:

So that's one area where the funding becomes almost doubly important it's not just the funding for the care it's the funding to stop families as you said I think sliding into crisis because the financial support is not provided by the social welfare system, oh boy.

Toby Porter:

It’s complicated.

Dr Linda Maynard:

If I can offer an observation on the sort of the direct payment system, that's designed to provide choice for families and to hold that system but in a, connected with the work that we’re doing with children with long term ventilation needs, the care packages for that group of children a lot of them don't fall into the palliative care criteria but a good proportion do. So, in the work that we’re doing, there’s considerable time pressure, in getting care packages set up for this group of children but then when they are discharged from the hospital environment there might be a direct payment system so a parent can recruit a carer. That parent is then required to teach that carer on how to care for their child so as a nursing team going in and observing that we're questioning the efficacy, the safety and the over-arching scrutiny and the accountability of that, so that’s a, not a, not an isolated incident.

Christine Jardine MP:

Is there anything you would like to add to that?

Maria McGill:

It's a slightly different system in Scotland and for some families it does work, that they employ carers or for as young adults and young people they will employ their personal assistants and for them it does work and for others it doesn't, simply doesn't and it may be that the local authority hasn't explained that you the local authority can take charge of that for them or they can actually do it themselves it can work either way and I think for some families it just feels like too much to do, and for other families who would like to take that on, it hasn’t been explained to them that they can do that. But again I know from an example some families that, they will see that when they make the changeover to that their assessments are that they're getting less funding and so just finding out they can buy less hours for their care.

Toby Porter:

I think I agree with that. I would say that two biggest variables that we see impacting on their introduction, or the success of their introduction is firstly, family situation. I remember I visited two families in quick succession, both with very seriously ill children, one of whom sadly died quite soon after I met, but that one couple were a married couple, two rather successful professionals; she was a senior accountant he was a junior accountant and they were able to deal with all aspects of their daughter's care as a sort of team and had a division of labour that one kept working, one did this and they were able to deal with the administration of the personal budget very effectively. Then literally two hours later I was in the home of a single mum with a child who needed literally round-the-clock care she said she couldn't remember the last time she'd slept for more than an hour unbroken and she found the personal budget extraordinary stressful and she also lived in a rural area so I don’t know if this collates with your experience but this lady lived in Herefordshire and she said well it’s fine having a budget but I can't find any carers or nurses and in a situation where in the old days that would have been the problem of the people directly they would have to find someone but in the personal budget system it's somehow that has become her problem because it, because she's running the enterprise and if what do you do in cases where that you cannot bring in the labour that you need because it doesn't exist so it's it's complicated I mean to be fair a lot of the young adults we work with are rather positive because they perhaps have different priorities. A lot of that yeah kids the young adults who we still see is young ambassadors of our hospice charity although they leave our service at eighteen, many actually majority of the kids were young adults, people living with muscular dystrophy in this particular category there seem to be much more interested in a more general personal assistant a carer who helps them with social media and doing the shopping and this and the other I have heard some positive things from that category just to be fair.