

RCSLT webinar – Developmental Language Disorder: What do the changes mean for your service delivery? Wednesday, 17th January 2018

Amit Kulkarni, Research Manager, RCSLT

Hello, and welcome to this RCSLT webinar on all things DLD, entitled "Developmental Language Disorder: What do the changes mean for your service delivery?"

My name is Amit Kulkarni and I'm the Research Manager here at the RCSLT. And I'm delighted to introduce our presenters today. Firstly, we'll have Dorothy Bishop, Professor of Developmental Neuropsychology at the University of Oxford. We also have Amanda Finer, who is a Highly Specialist Speech and Language Therapist at the Children's Integrated Speech and Language Therapy Service for Hackey and the City. And, finally, we have Lauren Longhurst, Research and Development Officer here at the RCSLT.

The webinar will be around one-hour long and there will be time for answering questions towards the end of the hour. During the webinar, you can use the Q&A buttons on the software to submit a question for the panel. You can submit these anytime and we'll endeavour to answer them in the Q&A session at the end, however, we have already received a large volume of questions for this webinar and so we'll try to group these into themes and we'll focus on those themes that come up most frequently.

Following the webinar, we will ensure that any topics we haven't covered are addressed on our DLD FAQ document.

Just to say as well, if you're experiencing any technical difficulties, use the chat button on the webinar software to send an instant message to Kaleigh Maietta and you can do that at any time during the event.

The webinar is being recorded and will go online with the slides after the event. Also, your feedback is very important to us, so if you're able to please do take the time to complete the two-minute survey that's going to pop up at the end of the webinar. But, in case you're rushing off straight away afterwards, a link will also be available in the email you receive following the webinar.

Just to say as well, if you do use Twitter, do use the conversation about this topic using the hashtags: #RCSLTwebinar or #DevLangDis.

So, before we get started, I'm just going to go over the learning objectives, to clarify the focus of the webinar in further detail.

So, after this webinar, we hope participants will be aware of the changes to terminology and diagnostic criteria for developmental language disorders. We will understand how the changes to terminology and diagnostic criteria impact on service delivery; have heard a case study example of a service that has successfully implemented these changes, the steps required to operationalise these changes and how this has impacted on their service delivery and, finally, to know where to find further resources to support changes to terminology and diagnostic criteria and support your service.

So, without further ado, I'm going to hand over to Dorothy.

Dorothy Bishop, Professor of Developmental Neuropsychology, University of Oxford

Hello, and welcome to everyone. It's a great privilege to be here to tell you a bit about the work that is behind the changes in terminology and really try and explain what we've done and why we've done it.

And the background... I usually use my taxi driver story to explain why I got interested in terminology. And it was because, for many years, when I used to sit in a taxi and the taxi driver would say, well, what do you do? I would say, 'I do research on specific language impairment'. And I would always get a blank look – whatever – or somebody saying, 'what's that'? And I learned to say, well, it's a bit like autism, or it's a bit like dyslexia, because I could be sure that the average man in the street would have heard of both of those conditions; they might know somebody who had autism or dyslexia, or they might have seen something in the media.

And I started saying to myself: Why is it that, with specific language impairment, nobody's ever heard of it? It's not that uncommon and, yet, it's completely a Cinderella subject.

I backed up this general sense by having the idea that I might look at research on different disorders, because I also had the impression that there wasn't a lot of research on specific language impairment. And I was able to access the American funder, NIH, publishes a big... on its website an account of all the grants it awards and how many thousands of dollars it spends on them – and these are huge sums; as you can see, these are thousands of dollars up on that Y axis. And what it shows very clearly is that there's a lot on autism, and there's been actually special funding provided for autism, special initiatives, but also Attention Deficit Hyperactivity Disorder (ADHD) has got quite a healthy level of funding; both of these are going up over time.

But if you look at the purple line, going along the bottom of the slide, that is all the research funding for not just SLI, but I've also bundled in other subjects that don't have a lot of research – dyslexia, speech disorders, dyscalculia and developmental coordination disorder. And there's a huge difference.

And the most interesting comparison is with ADHD, because that's a condition which, if you get clinicians to rate the severity of the impact on the child, it's very similar to SLI. And if you look at the frequency of the disorder in the population it's very similar to SLI and, yet, there's 15 times as much research funding for that condition that one has to say, 'why'?

Now, we don't know the answer to that question, but there were various things that struck me as I tried to do this exercise, and I had postulated various possibilities. But one of them was to do with the terminology. It's very hard to do a Google search for specific language impairment – you can do that, but you're going to miss a lot of things, because, a lot of the time, people who are talking about children's language disorders use other terminology. And if you put together three terms: a prefix, a descriptor and a noun, you can end up, I discovered, with 168 possible combinations. And I found 130 of these when I tried to search for research on this topic.

And 33 of them were quite commonly used, so it was really difficult to form a sense of this as a disorder, because people were not using the same language. And sometimes they were using different words to talk about the same thing. And sometimes they were using what sounded like the same words to talk about different things. And it struck me that this, at least, would be something that, if we could sort this out, it might help with achieving recognition.

Another thing that I did, as well as doing that literature search, was to set up with my colleagues, Maggie Snowling, Courtenay Norbury, Becky Clark and Gina Conti-Ramsden – the RALLI campaign – where we tried to raise awareness of what we, at the time, called Language Learning Impairment. And we've had some success with that with a YouTube channel, which features short clips about various aspects of what we called Language Learning Impairment. And we were very grateful for support from Afasic, the Waterloo Foundation and other funders of ours.

But, even then, trying to do that we hit at the terminological problem, because what were we supposed to talk about. We had some people saying, well, you're talking about specific language impairment; they didn't like that term, and other people wondering whether we were excluding other things.

So we had, as a second goal, to try and see could we do something about this very messy terminology and definitions in this field? And we got the opportunity to do so after we'd been running RALLI a little while a couple of years ago. We decided – that was particularly Maggie Snowling – and I had some resources that we could put into this to do a project which we called CATALISE, which would be to try and see whether we couldn't achieve a consensus on this topic. And we did this with my biostatistician colleague, Paul Thompson. And we had a lot of very helpful advice from Trisha Greenhalgh, who is the Professor of Primary Care in Oxford, who is familiar with using the method that we use – which neither Maggie nor I had used before. And this is the Delphi process, which is a process whereby you try and achieve consensus by getting an expert panel to agree on statements, but then to feed back the results that you get and see whether they can then still... whether you have to change the statements, drop statements, until you achieve some sort of consensus.

But before we could do that, we had to decide who is it we're talking about; what is it that we want to define? And we decided that our focus ought to be on children who needed help over and beyond what's usually available in the classroom. So speech and language therapists will be aware that they have a role in universal provision, in trying to ensure that teachers in classrooms are having language-friendly classrooms, which are benefiting everyone. And then there will be children who need additional targeted help in the classroom. But there are always some children for whom that is not enough and who have continuing problems that need rather more specialist assessment and intervention. And we are focusing on those in terms of trying to find some terminology for that subset of children who might need referral and intervention with a speech and language therapist.

The Delphi approach; I won't go into it in great detail in the interests of time, but, essentially, you go... you do it anonymously, which has a huge advantage, because it means that people say what they really think, and you do it online. And you need a panel of people who are experts, but you want to have a representation from a range of people. So we had predominantly speech and language therapists on our panel, from a range of English-speaking countries, including Ireland, US, Canada, Australia and New Zealand, as well as the UK. And some of these people were expert researchers in the field, others were practitioners. But what they had to do was to rate statements that we started out with. We would then feed back the whole panel's results from those statements. People could modify them, they could justify them, they could make comments, and the moderators – Maggie and I – were supposed to then put... modify the statements to see whether we'd get better agreement on the next round. And we went through this process twice. And then we ended up trying to write a consensus document, a manuscript, and again all the panel looked at that and sent further feedback. And this was really interesting, because we got a lot of comments, not just numerical scores.

The bottom line on terminology was that we did agree on this term 'Developmental Language Disorder'. It was very, very hard to reach agreement, there were so many different points of view and opinions, but this was what we ended up with. And I'm pleased to say that it's a term that does seem to now be gaining some traction.

So I'll just say a bit about what we mean by Developmental Language Disorder. It was generally agreed that if... since we're talking about that tier-3 level of children, we wanted to focus on children

who have language difficulties that impair social or education functioning, but also where there's an indicator of poor prognosis.

We know about prognosis mainly from longitudinal studies, where we've followed up children over time. And we know that having comprehension problems is one sign of poor prognosis, or having a wide range of different areas of language impaired. So we wanted to say, if you have that, it's reasonable to say you have a disorder. Because you have a problem that needs to be taken seriously, that's not likely to go away.

Then we subdivided it according to whether or not there was an associated biomedical condition. Now, Developmental Language Disorder was the term we want to use when there isn't, but we also had a lot of debate and discussion about what about a child who does have some associated condition such as a genetic syndrome, a sensorineural hearing loss, neurological disease, autism spectrum disorder, or intellectual disability. And we felt that it's important to emphasise that those children shouldn't just be excluded and not given any help; they have a language disorder and they need attention. But it's also important to flag up that they have a condition that is likely to cause broader problems.

We also, when we say 'associated with', we're not saying, 'explained away by', because there was concern that you get children who might, for example, have autism spectrum disorder and have disproportionate language problems that go over and beyond what we would normally see with that. So we're not saying, this is a whole explanation. But we're just saying, this is the context in which you understand their language disorder, and these children should still be eligible for assessment and intervention.

So language disorder we should see as a subset of a broader category of speech, language and communication needs, which would incorporate children who have atypical language, or speech for various reasons, but who wouldn't meet our criteria for disorder, which are for the more severe, longer-term problems. And Developmental Language Disorder sits inside that category of language disorder like Russian dolls; these are nested within one another. So that's the way to think about it.

And, in terms of the definition, it's also a very broad definition. And we did think of trying to put little circles inside that Developmental Language Disorder so that we'd have yet another set of Russian dolls nested within. But we felt that it wasn't feasible to do that. We discussed, should we, for example, try and specify subtypes of Developmental Language Disorder and we felt, no, because you could get so many variations that it doesn't make sense to say this, not that, because many children have more than one problem. But it is important that the type of problem is specified, because that obviously will affect the intervention you get. So we need an expert to look at is the problem with phonology, syntax, semantic word-finding, pragmatics and language use, verbal learning and memory, or some combination of those.

Then we came up against the issue of risk factors and, again, there was a lot of debate because sometimes these are used as exclusionary factors. We felt that the things that we've put here under the category of risk factors should not be used as an exclusionary factor. They have a probabilistic association with language disorder, but they can't be seen as explaining it away. And they include things like having a positive family history, coming from a deprived, impoverished background, or parents with a low level of education, neglect or abuse, having pre- or perinatal problems. Indeed, being male is a risk factor in that sense. More males than females have language disorders, but it's not a full explanation.

Similarly, there was a lot of debate about what about a child who also has other problems, like ADHD or motor impairments? Again, sometimes these have been used to say a child hasn't got a language disorder because it's not pure enough, not specific enough. And this, indeed, is why many people didn't like specific language impairment, because it seemed to imply you wouldn't have

anything else. And we knew that, in practice, it is very common to have some other conditions going alongside a language disorder. And the view was that these should be noted, but that they shouldn't be used as exclusionary factors, so that you can have some sort of combination of problems, it's not always just one single difficulty.

So what is new about what we're suggesting? Well, the main thing is that Developmental Language Disorder, or DLD, replaces SLI. And that the disorder is defined in terms of functional impairment, affecting either social and/or educational progress and poor prognosis, which obviously you can't be certain about, but we have quite a lot of information from longitudinal studies.

Now, the main thing that will make a big difference is that we do not use a distinction between delay and disorder, on the grounds that there's really no validation for that in the literature. And we looked very hard at this and we found that, often, people are using this in a way that really doesn't seem to be justified. Also we don't use a child's social background as any kind of criterion. And, importantly – and quite controversially – we don't use non-verbal IQ as a criterion for having a Developmental Language Disorder.

Now, I noted earlier that if a child had actually got an intellectual disability we wouldn't say they had a Developmental Language Disorder, we would say they have a language disorder associated with intellectual disability. But that is a category where you're not only a couple of standard deviations below the mean in terms of non-verbal ability, but it also has criteria in terms of how independent the child can be in various activities of daily living.

So there are many children who might, in the past, have been excluded because they had an IQ, say, of 80, which wouldn't put them in the intellectual disability range, but also is not a huge mismatch with their language skills. We are no longer excluding those children; we would say those children have a language disorder – Developmental Language Disorder. And these additional problems that you might have would be descriptors rather than exclusionary factors.

So I will just go over some common questions, but obviously I'm sure you will have many more. But the main one that we have had is, what about language delay? Because this has been so widely used in the UK and we're really saying, we don't think it's valid. So it was rejected, simply because there was no evidence to support that distinction. It's been around a very long time, and many people are taught to make that distinction, but there's remarkably little evidence to support it. And, indeed, right back in 1987 in one of the first studies I ever did I followed children who had a spiky profile with different levels of impairment and different language tasks, as opposed to those who had a rather flatter language profile, and found that the better prognosis was for the spiky profile. But it was the children who had that profile who got better access to therapy, because that was seen as a sign of disorder, whereas the children who had rather more impaired skills across the board tended to not get access to therapy, because people thought it was a delay; that doesn't actually make a lot of sense.

The other thing that we found was that people were saying that language delay is something caused by poor environment, but there have been studies now comparing children from deprived and nondeprived backgrounds in terms of their language skills and their prognosis and they really don't support making that distinction. So it's evidence-based that we say that this distinction really doesn't seem to be one that we should be adopting.

The other questions that we've had, one of them is what about if you've got a younger child? Because most of... in order to meet our criteria for having functional impairment and poor prognosis, often the child would need to be aged about four or five before you could be certain, although you do get younger children who have severe enough problems that you would know they had a poor prognosis. Quite often in a three- or four-year-old, you're not really sure if they might actually subsequently get more into the normal range in terms of their language skills. So these children who have not yet got to the point where you could give a diagnosis were not really the focus. Because we're concerned with those requiring tier-3 specialist provision. And we wouldn't recommend using the term 'disorder' unless the child has got more persistent problems. And, indeed, some of those from educational backgrounds on our panel were very opposed to using the term 'disorder' in this sort of context, and I think rightly so.

But we would say that these children would come under the umbrella of speech, language and communication needs and they could be referred to as having language difficulties, or language needs, but you really don't want to put a diagnostic label on them that implies they've got a long-term persistent problem until you're fairly certain that they have those sorts of characteristics. So certainly we're not saying those children shouldn't be the focus of clinical attention, but we're saying we just wouldn't call them DLD.

The other group of interest is Speech Sound Disorder. So Speech Sound Disorder is a general term and, although in theory people will often say you should distinguish children who have a more linguistic type of Speech Sound Disorder from those with motor origins; even the best experts tell us that it's very hard sometimes to make that distinction. And it's quite useful to have a term like Speech Sound Disorder, which doesn't make any inferences about the cause of the problem. And they key thing about it is it's a disorder that can occur on its own or with DLD, so you do see it accompanying DLD, but where it does occur without accompanying problems with language, expression or comprehension, things like grammar and vocabulary, we would say if you've got those sorts of speech problems which are really quite common in kids, or if you've just got poor phonological awareness, it wouldn't qualify for a diagnosis of DLD, mainly because we know that the prognosis is usually pretty good for those kids, so Speech Sound Disorder rather than DLD in those cases.

If you put it all together, you end up with this sort of diagram, which looks horrendously complicated and there are various versions of this where people have tweaked it a bit, just because some things were not entirely clear. But this is the version that I've currently got on my system. And, basically, the point you want to make from it is that, although it's very complicated, it's really just capturing the Russian dolls again. I mean, it's really showing you that you've got the outer, pale yellow circle with a lot of things there that do involve speech and language, but wouldn't meet criteria for the DLD.

And within that you've got the language disorder conditions which have got the poorer prognosis that the more severe impact on function. And, within that, you've got Developmental Language Disorder, which can take many manifestations with different areas of impairment. And sometimes that can co-occur with Speech Sound Disorder, and sometimes it doesn't.

So that's trying to summarise a very complicated picture.

A fourth question we've had is people were getting very concerned about the fact that we will now include children who don't have a big discrepancy with IQ, who were previously excluded from intervention because their problems were not meeting the criteria for being specific.

So we can get an idea of how many children these are going to be from a very recent population survey in Surrey by Courtenay Norbury, who was able to use criteria similar to those that we've specified here and get estimates of prevalence in Surrey. And what she found was that there were about 7% of children who met criteria for DLD overall and about a third of those had low average IQ. So, from 70-84. And then there were a further 2.3% who had language disorders with an associated condition.

Now, her research really vindicated our decision not to draw the distinction with non-verbal IQ, because she found no differences between those with average and low average non-verbal IQ in terms of the severity of the language deficit in terms of social, emotional and behavioural problems, or educational attainment. And other studies have failed to find differences in response to intervention. So it really does seem, at the moment, not justified to make that separation.

What she did find was that, if you took the children who had language impairments associated with a known medical diagnosis or with intellectual disability, they did have more severe deficits on multiple measures. So there did seem, again, some justification for keeping those together in a separate group.

But the key issue that I think emerged from this exercise is we started it, really, with just the aim of raising awareness and trying to get a common language, but it became very clear that it raises a lot of issues about how you decide access to services, which will be very relevant to the people listening in here, I hope. The thing is that the speech and language therapy profession obviously has to consider terminology in relation to who gets intervention, and it's very clear that labels do make a big difference as to who does or does not get various sorts of intervention.

And one of the things that was clear when we tried to use evidence is that there's still a really rather weak evidence base in determining which children will benefit most from which intervention. So people tend to make decisions based on habitual practice, or that they just assume that intervention will work. And sometimes there's very strong local pressures to adopt one diagnostic terminology rather than another.

But we felt that one of the things we could say on the basis of this exercise that we did is that there really is an urgent need for people to get together, several centres combining, to do intervention research with reasonable numbers of children, because you're not going to be able to get funding unless you can demonstrate the impact of speech and language therapy. And it's really important to look at that for different types of children with different characteristics.

And, when doing that, it's also important to not just focus on changes in language test scores, I think. Because one of the things that concerned us was the realisation that children sometimes only get intervention on the grounds that there's pressure to intervene with children where you might be able to discharge them after eight weeks. Whereas many of the children we're talking about have got long-term problems; that's how we've actually identified them, and you're still able to have an impact on those children, but it might be seen more in terms of their social and educational functioning.

And it's really, if you draw a comparison with autism, we're really saying that there are many children with language disorders; they're not going to be cured, but, nevertheless, management from speech and language therapists might make a big difference to their outcome. And those children, I think, have sometimes been rather neglected in the current system.

So, basically, the conclusion, really, is that we're using Developmental Language Disorder. We're not talking about a single homogenous condition, and I should stress that no label is perfect. And I'm very interested to hear from people who are coming up with children who may not neatly seem to fit into this categorisation, because I think we will, no doubt, revisit it again and tweak it a bit in the future the more we consider cases who don't fit in neatly. So please feel free to contact us about that.

But, for the moment, we're hoping that the consensus we've achieved so far will move us forward in raising awareness, improving services to children and allow us to do better research by just using a common language.

I want to move on now, though, to take you over to Amanda, who's going to tell you more about how she's been implementing these changes in services in Hackney.

Amanda Finer, Highly Specialist SLT, Children's Integrated Speech and Language Therapy Service for Hackney and the City

Hello, thank you, Dorothy.

Hi. So my name's Amanda Finer and I'm a Highly Specialist Speech and Language Therapist working for Children's Integrated Speech and Language Therapy Service for Hackney and the City. And I specialise in working with children with DLD and speech disorders.

I'm going to talk to you today about how we've been implementing DLD in Hackney and the City. I'm going to start by telling you a little bit of background about our service and then talk to you about all the different people that we've been talking to, to say that we're able to implement DLD.

So, first of all, who we are. I thought it was useful for you to have a bit of background information about our service, because I think it helps for you to then understand how we've been able to implement DLD and how we've been able to do it as quickly as we have in such a far-reaching way.

So we're the Children's Integrated Speech and Language Therapy Service. And this is our title because we're funded by multiple Commissioners. Some of them are listed here, but this is by no means everybody. There's a very long list and, thanks to this, we're able to pool our resources and we've created a cohesive service.

Also, because we're funded by multiple Commissioners, we're far-reaching, so it means that we see children and young people of all ages with speech, language and communication needs and eating/drinking difficulties, no matter whether they've got an Education, Health and Care (EHC) plan or not. And it means that anyone can refer to our service. And I think, because of all of this, we're able to aim to be a needs-led service.

So, within our team, we think that it was really important to start with developing the skills, the knowledge, the confidence of the speech and language therapist within our team first. We didn't want other professionals and families to be coming and asking a speech and language therapist a question and for them not to feel like they have the knowledge or the confidence to be able to answer that question. And so we really wanted to make sure that they had the knowledge so that we were all sharing a consistent message.

So, to help with this, we developed a DLD network. So it's very much been a team effort. We've had support and guidance from a Service Manager and a Clinical Lead Speech and Language Therapist, so 8b and 8a level. There's me as a Highly Specialist Speech and Language Therapist and we have a group of therapists across early years, primary and secondary, who have all got specialist skills in DLD and an interest in working with these children.

And we formed a network so that, together, we can apply the theory from CATALISE and implement DLD in our service. We think there's a lot to do; so it's too much for one person and, actually, it's quite important to have a team effort. And, also, because we're such a far-reaching service, it's important that there's lots of people who are able to spread that consistent message.

So we've been sharing the information with our whole speech and language therapy team. DLD makes up a large proportion of our caseload now and therefore we've got to make sure that all speech and language therapists are able to diagnose DLD. To be able to make sure that they feel confident to do that, we've been holding CPD twilight sessions for all speech and language therapists where they can come along to find out about Developmental Language Disorder, the criteria,

impact, as well as assessment and therapy and these CPD twilight sessions continue throughout the year.

And then we've also attended meetings with individual teams within the service, so that we can provide more specific information relevant to the children that the therapists are seeing within that team and the age group that they're working with.

And a message that we've very much been trying to share with everybody is not to get hung up on IQ and to try and talk around other ways you can find out about children's learning.

Something else we do is we offer specialist support packages. So the specialist DLD therapists, many of whom are in the DLD network, provide second opinions, advice and support over the phone or face-to-face and also we can work with the child's linked speech and language therapist to diagnose, help to assess and diagnose or to deliver a therapy package. But what's important here is it's delivered alongside the linked speech and language therapist. So that we are upskilling the therapists working across early years primary and secondary.

We've also been working with other professionals. There's lots of different people we've been working with and lots of different things we've been doing. And if you want more information about how to work with a specific group of professionals, you're very welcome to ask me a question or my contact details are at the end. I've put a few useful tips on the slide that you can read at your leisure. And I thought I would just highlight a few things today.

So, first of all, the first thing that we did was to meet with some of the key stakeholders; who was the head of the SEND at the Learning Trust, the inclusion team leader and members of the DLD panel. So these are some of our key stakeholders, and we thought it was really important that they were on board and fully understood the changes first.

It was our speech and language therapy service manager who chaired this meeting to show the importance of that meeting. And I think meeting face-to-face really helped us to iron out any confusion or misunderstanding and has really helped to ensure that we haven't had barriers to implementing DLD in Hackney and the City.

At this point, I'll just explain what LRS – or 'Language Resource Schools' – and DLD panel mean. So we have two mainstream schools in Hackney... primary schools in Hackney, who have a certain number of places for children with DLD and for children with speech disorders. And these children receive a very high level of speech and language therapy, much higher than they would receive in their mainstream school. And these children... well, the children who are... we decide which children go to... which go to the... which children will go to these language resource schools by... they go to our DLD panel. And it's the panel that decide the children who would best be suited in these schools.

So the panels are made up of me, as a speech and language therapist. We have a specialist teacher, an educational psychologist, two inclusion managers from the two LRS schools and a member of the SEND Department at the Learning Trust.

A few things that I just wanted to share with you from observations of having worked with other professionals. Of course, you'll be sharing information on the changes to terminology and criteria and then providing some useful specific information, depending on who you're talking to. But, actually, going in there and having open discussions rather than going in to deliver formal training has been really valuable. We found, actually, that it's important to really recognise the knowledge of other professionals. And, really, as speech therapists we, for those more complex cases where we're not sure whether language is definitely the primary area of need it's really useful to have other professionals on board. And those are the professionals who've really seen their value for

those more complex cases. They want to be involved and a conclusion with whoever we've spoken to has been that, actually, open communication for these children is key, and open communication as early as possible is key.

Our educational psychologists have thought, for those children where we're not sure whether it's language or learning that's the primary area of need, perhaps we would work together to assess these children and write joint reports. And that's a really exciting move that we're hoping to pursue further.

Something we've done that's been helpful for professionals is videoing DLD children and young people. We've found that it helps to link the theory to practice. And, actually, by taking some of the more complex cases to... videoing some of the more complex cases and sharing those it's quite interesting to sit with all our different professional hats on and discuss those children and it just shows, again, that importance of open communication for these children.

We've found that we haven't had any barriers when we've been speaking to other professionals; everyone has been happy to take on the new term and keen to be involved. And also that actually we've found it's been very helpful to have a common language when we're talking to each other and with families.

So working with parents and young people, we've found that face-to-face discussion has been really key, so that families don't feel anxious and to ensure that EAL families fully understand. We're a needs-led service, so we have had some children on our caseload, perhaps for quite a long time who've never had a diagnosis of anything and now we may be giving them a diagnosis of DLD. So it's important to meet face-to-face and be able to explain this diagnosis sensitively.

Parents' and carers' main questions have been around what the change in name may mean for the input that a child receives. And, because we're a needs-led service, it doesn't change the input; we support the children based on the need that they present with at that time, and over time. And that will continue; that doesn't change because the name of the diagnosis has changed.

Something else they've wanted to know a lot more about is what we mean when we say it's a lifelong condition. This is something that we've had to explain gently. And parents have wanted to fully understand this.

I've put a clip here of something from Twitter. So we made leaflets about DLD, which we shared on Twitter. We tweeted about them. And HIP – which stands for Hackney's Independent Forums for Parents and Carers of Children with Disabilities – got in touch to us for copies of those leaflets. And I think this just shows the power of social media and being able to spread the message. It was because of Twitter that we were able to be a lot further reaching and share those leaflets a lot more widely with families.

And, finally, when working with young people, we've written a programme to teach key stage-2 children and beyond about their diagnosis of DLD and this includes a parent workshop, because we think it's important that parents and carers, first of all, are on board with their children learning about their diagnosis. And, second of all, that they feel confident in what DLD means, so that if their child comes home to talk to them about it, they have the knowledge and the skills to be able to discuss the topic with their child.

So, finally, we've been raising awareness more generally in the community as well. On DLD awareness day, we had a stall for professionals and the public and we chose to hold this stall in a building where we knew that a range of professionals were based, as well as members of the public who come to visit the library that's also based in this building. We also were interviewed by Hackney Gazette about DLD and they wrote an article, which was fantastic. And we wrote... made a poster,

which we have sent out to all GP surgeries, children's centres and libraries in Hackney and the City, and all the speech therapists have taken copies in to every school that we visit.

We've made leaflets for early years, primary and secondary, parents and carers and for school staff. And, finally, just to reiterate again that we're active on social media and we've found that's been a really key way of sharing the message with the wider community.

So here are our contact details. So you can either ask me a question at the end or please don't hesitate to get in contact with us. We're happy to help and share what we've been doing in more detail.

Thank you very much. I'm going to pass you on to Lauren.

Lauren Longhurst, Research and Development Officer, RCSLT

Thank you, Amanda.

Yeah, so I'm going to talk a little bit about a case study, following on from Amanda, of a private practice setting and implementing the changes. And then also talk about some of the resources that we have available to you.

So Sarah Buckley's Therapy Ltd. have started to implement the new changes for Developmental Language Disorder within their practice and these are just some of the key things that they've worked through and actions that they've taken to do so.

So, as a practice, evidence-based practice is very important to them and they try to stay up-to-date with the current research in Speech and Language Therapist and, therefore, the CATALISE project. The topic was discussed in a staff workshop, using Susan Ebbels' summary of all the changes with terminology and criteria and this is available on the RCSLT website.

Once the staff were confident and on board with the terminology and the changes, the service then changed over to using Developmental Language Disorder and started using it in reports and documentation.

In order to do this, they created a short summary for parents, explaining why there has been a change and what this entails, in language that was accessible and easy to understand. In addition to this, they engaged with those parents and service users who may be impacted by the changes to discuss any concerns that they might have and questions. And these changes were implemented in consultation with key stakeholders as well.

Training was given to school staff, especially round the discrepancy between verbal and non-verbal IQ, as this was no longer being used as a key indicator of a language disorder. And it's also led to a review by the team of the terminology they are using in other clinical areas, to ensure that they are being consistent and delivering that consistent message.

In terms of current RCSLT resources, the 2016 International Journal of Language and Communication Disorders Winter Lecture was... Dorothy Bishop led on this and focused on changes in terminology and diagnostic criteria. So if you want more information about the CATALISE process, we recommend looking at this. The evidence and research section on the clinical webpages for language disorder have been updated with recent studies and will continue to be developed as the new website comes into play.

We've also published a briefing paper on Developmental Language Disorder, which summarises the changes and the implications for clinical practice. Alongside this, we developed an FAQ document to

help clinicians to navigate these changes. We're aware of lots of questions that have come in for the webinar and these will all be added to this document, to reflect your concerns.

We've also got presentations from a DLD workshop that was held in the summer for Hub representatives. And also RCSLT conference presentations, subject to consent, are also available. We've got infographics on key messages about DLD. These have been developed and shared on RCSLT social media channels and are available for you to also use.

We've been liaising with government to try and develop the awareness of SLCN as a whole and also DLD a bit more specifically, including the changes to terminology and criteria, and this will be ongoing. Alongside the children's strategy work at the RCSLT, which aims to develop a shared understanding of good practice and outcomes.

We've also got some information and resources for SLTs working in school settings and also resources about how to commission speech and language therapy services.

We would like to remind members that it's a really good ideal to liaise with your local Hubs and CENs – maybe on Basecamp – as there's a lot of discussion around Developmental Language Disorders at the moment, and you might notice a lot of study days popping up as well. All these resources are available on the link that you can see on your slide.

In terms of what we're doing in the future, we're collating and sharing useful resources that are produced and used by services when implementing the changes – so some of the resources that Amanda was talking about. If you have similar resources that you think have been really useful to you, we're really keen to hear from you, so that we can make these available to other people.

We also are running a research priorities project. DLD was identified as one of the key clinical areas where research priorities are needed. This was also highlighted by Dorothy earlier. These treatment uncertainties have been identified and are being mapped to existing research, so there will be a workshop taking place later on this year to generate new research questions.

In addition to this, a PowerPoint package will be developed to support the delivery of training to SLTs to ensure that consistent messaging. We're also working with the National Association of Head Teachers to create guidance for schools on commissioning Speech and Language Therapists. In order to raise further awareness in the wider population, we're developing a factsheet highlighting the key messages about DLD and we'll also hold a system leader round-table event to discuss how changes in terminology and criteria can be implemented.

And now I will pass back to Amit for the question and answer session.

Amit Kulkarni, Research Manager, RCSLT

Thank you so much, everyone, for those fascinating presentations. As Lauren says, now we're going to think about answering some of the questions that we've had, both via email prior to this event and also coming in as we've been speaking.

I think I'm going to start off with a question that's around the importance of these changes. The question was as follows: children rarely get EHCPs for DLD. So why is this new terminology so important? And, if possible, I'd like to go to you first, Dorothy, and then follow up with some comments from Amanda.

Dorothy Bishop, Professor of Developmental Neuropsychology, University of Oxford

Yes, I think sometimes it just seems why do we need all these changes? But it really goes back to what I started with, about ease of communication between professional groups. And also, from the

point of view of families who are affected, they like to be able to Google something, be able to look it up and get a consistent answer. They like to be able to contact other people, other families who are affected by similar conditions.

So it really facilitates communication – not just between professionals, but also between those who are affected, and also for researchers it's fairly crucial to at least have some common definition. So I think that's the main reason why I think it's important.

Amit Kulkarni, Research Manager, RCSLT

Fantastic, thanks so much.

Amanda Finer, Highly Specialist SLT, Children's Integrated Speech and Language Therapy Service for Hackney and the City

First of all, I just wanted to say that, in Hackney and the City, DLD is now included under the Communication and Interaction Criterion for any EHCP and children who are very vulnerable where the language impairment's having a huge impact on their functioning, it is possible to have an EHCP. But also we've found it very useful to have a term that we're all using, so that there's a common language when working with families, when we're talking to each other, when we're talking to other professionals. And other professionals have really welcome it as well, actually; they haven't been sure what term to use and have seen lots of different terms in our reports. So to be much clearer, they've said, will really help them as well.

Amit Kulkarni, Research Manager, RCSLT

Yeah, I would agree. I think this consistency can only help to raise awareness of the difficulties. And, hopefully, through having a consistent label and through raising awareness of this label, maybe that will be what will allow us to get to the point where EHCPs become more possible for children with these difficulties.

I'm going to move on to a slightly different area. So I'm thinking now about older children and adults with such difficulties. One of the questions we've received is: What terminology do you recommend using for older children, young adults and adults with difficulties in this area?

Dorothy, could I come back to you again?

Dorothy Bishop, Professor of Developmental Neuropsychology, University of Oxford

Yes, I think one of the things that's been important about the whole awareness-raising exercise is the number of people who have emerged as... not just older children, but also adults, who, either themselves, think they're affected, or they're parents of somebody who, in adulthood, they suddenly recognise that what they had was a DLD.

One of the reasons that people had for being not so certain about the term 'Developmental Language Disorder' is what happens when you get to adulthood it seems a bit odd to say 'developmental' if you're a 45-year-old.

But the answer to that, really, was very much in line with what happens with developmental dyslexia, in that adults with it just say that they're dyslexic. And so I think adults who have a history of Developmental Language Disorder might not want to use the full DLD as they get older can just talk about themselves as language disordered.

But certainly there has been very little recognition of these conditions in adolescents and young and, indeed, older adulthood. We've found that, for example, student disability services regularly diagnose people with autism, with dyslexia, with ADHD, but not... and with DCD, dyspraxia, but again not with Developmental Language Disorder. And we're trying to really change that. And, again, this is another thing where we think the label might be useful in really just drawing awareness to a group

that are otherwise, sort of, would rather disappear off to the horizon and don't really get much attention and nobody's lobbying for them. So we hope that that will change.

Amit Kulkarni, Research Manager, RCSLT

Thank you. Amanda, I don't know if I can come to you for this next question. We've had one come in which says: The work that you've done in Hackney sounds absolutely fantastic. Can you tell us how long it took to achieve this?

Amanda Finer, Highly Specialist SLT, Children's Integrated Speech and Language Therapy Service for Hackney and the City

I think it probably took about a year. I think, last year [2017], around March time, we probably started talking to speech and language therapists about the changes to the criteria and the terminology. And I would say, really, things have really started to ramp up in September, starting with the DLD Awareness Day. And then things have moved on from there.

Once we start talking to one professional, others hear about it and have asked us to come and talk to them as well. And, yeah, I would say since September, really, that things have really started to ramp up and we've been really busy with what we've been doing.

Amit Kulkarni, Research Manager, RCSLT

Fantastic. That gives us an idea of how long it took in your Trust.

Another question has just come in about the relationship between DLD and previous diagnoses of SLI. And I'll just open it up to whoever would like to take the question. It's as follows: What happens with the young people who currently have a diagnosis of SLI; do we just change terminology in reports following information provided to parents? I presume an extension of this is also: Do we continue to provide support? I don't know if anybody would like to answer this.

Amanda Finer, Highly Specialist SLT, Children's Integrated Speech and Language Therapy Service for Hackney and the City

I'm happy to answer this, yeah.

So that's exactly what we've been doing. We've been speaking to parents first and then changing the terminology from there. So we've got a set paragraph that our speech therapists can use if they want to in reports or in an EHCP report. We've got a letter that we can send out to let anyone who's involved with the child know about the change in the diagnosis. And then the leaflets as well.

So, yes, just what you said, really, provide the information to parents and then, yeah, just go ahead and change the terminology and everyone's been very open to it. We haven't had any problems doing that.

Amit Kulkarni, Research Manager, RCSLT

Fantastic. Is there anything else you'd like to add on this issue?

Amanda Finer, Highly Specialist SLT, Children's Integrated Speech and Language Therapy Service for Hackney and the City

Maybe... Sorry, just to add also speak to schools as well. Maybe train the schools, the members of staff who are involved with that child; I think that's key as well. To make sure key stakeholders are on board before sending out information in a report.

Amit Kulkarni, Research Manager, RCSLT Yeah.

Dorothy Bishop, Professor of Developmental Neuropsychology, University of Oxford

And I guess the only other thing to say is, you know it shouldn't affect your... I mean, whether you get intervention or not should depend on your language problems, not on the label that somebody stuck onto you.

Amit Kulkarni, Research Manager, RCSLT

Absolutely. And I know, Amanda, I've heard you talk about this being a needs-led... your service being a needs-led provision, and I think that would very much fit with the approach from the RCSLT as well.

I'd like to move on to a slightly different area now. We received a question about higher education institutions. And the question asked something like: Has work been done with universities to develop and update the use of terminology and criteria on courses?

Lauren, I know that, through the RCSLT, we've been working with this. I wonder if I could come to you?

Lauren Longhurst, Research and Development Officer, RCSLT

Yeah. We've been updating the curriculum guidelines for university courses in the UK and the steering group have been working to include the new terminology within this. And we've been also checking that terminology that's used with experts in terminology and in DLD.

Also, another thing to mention, a lot of the people researching into the DLD will be based at some of those universities. So we would hope that the university courses are really on board with that new terminology and will be starting to implement that and explain to the students the process that has been gone through.

Amit Kulkarni, Research Manager, RCSLT

Fantastic, okay. We've had quite a few questions through about resources. So one of the questions was around looking at resources to help change entrance criteria for language resource bases. And another question was just a simple question around where resources can be found.

Lauren and Amanda, I don't know if I can come to you for both of these questions.

Lauren Longhurst, Research and Development Officer, RCSLT

Yeah, I think just highlighting again that we really are keen to pool our resources as a profession and if anyone does have any resources out there that they're using that have been successful, we're really keen to see those and to share those further. And that resources will be available to you on the link that I gave in one of my slides earlier. So just to highlight that, we really are keen to share resources.

Amanda Finer, Highly Specialist SLT, Children's Integrated Speech and Language Therapy Service for Hackney and the City

And in terms of panel and children going to a specialist unit, or provision. So we're very lucky, first of all, in Hackney that most of the schools are buying in speech and language therapy. So children are getting a certain level of speech and language therapy in their current school. And also our DLD panel is made up of professionals who would be working day-to-day with these children – educational psychologists, specialist teachers, me as a speech therapist. So that helps us when it comes to sitting down around a table and making decisions about the best children who... the children who'd benefit most from attending the provision.

So we've come up with a checklist that I'll go through with you, in case this helps. So we've said that speech and language is the primary area of difficulty. We don't give assessment levels or cut-off points, because we know that it's around being a functional impairment, impacting on their social,

behaviour, learning. So we haven't been giving any cut-offs. But we have said other difficulties, such as attention and listening difficulties, difficulties with play or social, emotional, mental health difficulties, some learning difficulties, they can all coexist or be related to the language difficulty. But language must be the main area of need. And this level of need must be at a level beyond which the current mainstream setting is likely to be able to support.

So we're asking the therapists and the schools who are sending the children to be able to try and provide information to show that. We've said that the children must have potential to take advantage of intensive level of language or speech intervention. So, really, we ask for the speech therapist to carry out a block of intensive therapy with the child to see whether, when they are able to access more intensive intervention, it makes the difference.

We know that it needs to... the language impairment needs to be significant in both languages – so that's important.

We have said that social communication, interaction skills can be a mild area of need, but we don't want this to be the main area of need. It can, of course, be associated with their speech or language difficulty. And so, together, this information we ask for a detailed report from a speech therapist. We'd like results from a hearing test. Evidence of their learning profile, is what we ask for. So for actually a long time in Hackney, EPs haven't been assessing non-verbal IQ; we've been told that it's an unreliable measure.

And so, for a long time now, educational psychologists in Hackney provide us with a child's strengths and needs in all different areas of their learning. So we are used to working in that way when it comes to looking at children's learning anyway, and trying to decide together what the primary area of need is.

And so when we're asking for information about the learning, we've said this can come from the teacher, or another educational professional, perhaps the SENCo who knows the child well. We'd like to some National Curriculum attainment levels, or something similar, where it's available, or maybe some detailed information from the parent, if it's a child who's five and hasn't been in school for very long. Perhaps a paediatrician report, or information from an educational psychologist, if it's felt to be necessary, but it's not essential. And then, of course, parent consent is key; they don't have to have an education healthcare plan to come to one of our language resource schools.

Amit Kulkarni, Research Manager, RCSLT

Fantastic. Thank you. We've had quite a few questions about related conditions. So we've had questions about autism, about selective mutism and about learning difficulties.

Dorothy, I don't know if I could steer these your way and if you could just quickly disentangle the process that CATALISE came up with?

Dorothy Bishop, Professor of Developmental Neuropsychology, University of Oxford

Ooh, all in a minute! This was very, very contentious. I'll just take the example perhaps of autism, because I can't talk about absolutely everything. But the difficulty was that we had to decide, were we going to say that we would try and make a distinction between children who had autism with DLD, or were we always going to keep DLD separate?

And we decided that although we recognise that there's a huge variation in the types of language problems children with autism have, that we were not going to try and make people to make that distinction, because it was just too difficult. And that what we would rather do, therefore, is say you cannot have DLD and autism; we're going to say DLD is DLD, is defined in terms of not in addition having autism. Doesn't mean you can't have autistic features, but we're saying if you've got a primary diagnosis of autistic spectrum disorder then we would say you've got a language disorder

with that. But we would keep in mind that, nevertheless, that language disorder might take very many different manifestations, it would need full assessment. And, in some children, it might need speech and language therapy on top of any sort of specific intervention for the autistic features.

So it really comes back again, I think, to having a detailed assessment of the whole profile of the child. The terminology, you know, we're trying to fit children into little boxes and, of course, they don't fit; there's all sorts of variations out there. But we felt just to stop people having to try and decide, is this actually completely compatible with the autism, or is it a little bit different, or... It was just too hard a decision to expect people to make, so we said, well, we'll just note that they've got both conditions and then if you're a speech and language therapist really evaluate the language and make a decision whether intervention can help.

Amit Kulkarni, Research Manager, RCSLT

Absolutely. Thanks so much. And I'd just like to extend that by saying that, from the Royal College's point of view, we very much advocate an evidence-based approach to practice. We feel like the findings of CATALISE and other work in this area has really led the way on this. And we'd therefore very much recommend using this information in terms of guiding your practice.

Unfortunately, we have run out of time. So thank you so much to all our presenters, who've been fantastic. Thank you so much to all of you for participating as well. My apologies that we haven't managed to answer all of your questions, but, as I said, we'll endeavour to capture as many of them on our DLD FAQ document, which we'll update after this event.

Just to remind you that the presentation, the recording and the transcript will be available online, along with the FAQ document that I was talking about.

So I'm going to wrap up now, but just to let you know, please do join us for our next webinar on 23 February entitled 'Public Health and Communication Needs: Can the UK afford not to listen?'

Thank you very much.