

Lidcombe News



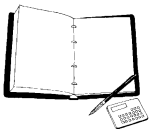
January 2013

Edition 45

It would seem that snow and floods, and sun and wind are the themes of the month as I embark on this winter's edition of Lidcombe News. While here in the UK we have worked our way through cold and wet, our colleagues down under have endured blisteringly hot days, bush fires and now cyclones. But to all of you, north, south, east and west, winter, summer or whatever the season, we send you our best wishes for a happy and healthy new year!

Lidcombe News meanwhile carries on with its regular features, Dear Sue and Just Explain That Again, and we also take a look at the turn that the latest research into the Lidcombe Program is taking- how the programme is being translated into your everyday clinics. While as yet we don't have many results to give you I thought it would be of interest to those not involved to see what is happening and why it's important, and how the whole process works. We have therefore reports from Sue O'Brian from the Australian Stuttering Research Centre who is overseeing the project and from Rosemarie Hayhow and Rosalee Shenker who are collecting and co-ordinating the UK and Canadian results.

First though, as ever, we have news about Link Days and workshops in the UK. (Workshops taking place in North America may be found on the Montreal Fluency website, and the Australian Stuttering Research Centre also has its own CPES section).



DATES FOR YOUR DIARY

Norwich is holding a Link day on **Tuesday, April 16th 2013** from 9-3.

Venue: 40, Upton Road, Norwich, NR4 7PA. Bring/buy your own lunch.

Contact: Sally Lelièvre for details, directions etc. on tel. **01603 508946**, or **email: Sally.Lelievre@nchc.nhs.uk**



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Contributions to Mary Kingston. Send your ideas and questions to:
Email: kingstonamee@talk21.com I can't promise to include everything and have to reserve the right to edit contributions as necessary. But I'll do my best!

The Northwest will be holding its next Lidcombe Link Day on **Tuesday 14th May 2013** at 1 pm for a 1.30 start.

Venue: Beckwith House (1st Floor), 1 - 13 Wellington Road North, Stockport, SK4 1AF. People can park in Heaton Lane Car Park which is just around the corner from Beckwith House, (pay and display - approx £2.20 for 3 hours).

Contact email: Michele Allen on michele.allen@lancashirecare.nhs.uk or telephone: 0161 426 5200.

Central England is holding its next Lidcombe Link day on **Wednesday 15th May 2013** from 13.30 – 16.30.

Venue: Group Room 2, City of Coventry Health Centre, 2, Stoney Stanton Road, Coventry CV1 4FS. Pay and display parking is available on site. The **agenda** is: further SR reliability practice, case studies, sharing resources (PLEASE bring lots of ideas to share) and up-dates from any research or articles.

Contact email: Debbie Middleton on Debbie.Middleton@covwarkpt.nhs.uk or telephone: **024 7696 1453**

COURSES AND EVENTS



*It has been agreed by the Lidcombe Program Trainers Consortium that the two day workshop (three days in countries where English is not the first language) is **only** for Speech and Language Therapists (Speech Pathologists etc.) and students in their final semester. It is not designed for parents (unless they are qualified SLTs), TIs or members of other professions e.g. psychologists, doctors, teachers.*

There are currently no new workshops being advertised in the UK. Contact Mary Kingston on email: kingstonamee@talk21.com for news about future courses as they come on stream.

For information about the previously advertised course in **Norwich on March 7th and 8th 2013** contact

Sally Wynne: lidcombe@live.co.uk or

Mary Kingston: kingstonamee@talk21.com

The Lidcombe Program in the Community

Sue O'Brian

Sue is senior researcher / lecturer at the Australian Stuttering Research Centre at The University of Sydney. She has worked in the field of stuttering for over 35 years. Her current work involves the development and evaluation of new treatments for adults and children who stutter. She was one of the original developers and trainers of the Lidcombe Program.

For many years, SLTs have been encouraged to use evidence-based treatments in their clinics. We read the research, we are impressed by the outcomes and we are keen to use the techniques in our clinics and to reproduce the same outcomes with our clinical caseloads. We are also encouraged to regularly compare our personal clinic benchmarks with those reported in clinical trials research. But is this fair? Do the stuttering children in your clinic meet clinical trial benchmarks? Do you even have a similar caseload to the research cohort? Have you ever said, "It's all very well for those researchers in their ivory towers but the program just doesn't always work like that in real clinics".

There is often a gap between the conduct and outcomes reported from clinical trials research and what can be achieved in "real world" clinics. Clinical trials usually employ specialist clinicians and recruit carefully selected participants. In contrast, the real world is full of things that may complicate ideal treatment delivery: large caseloads, long waiting lists, service restrictions, non-compliant children or parents, children or parents with associated language or behaviour problems, to name a few. Such factors along with the complexity and cost of the treatment, and availability of resources, infrastructure, training and support will have a significant effect on both treatment fidelity (how closely SLTs are able to adhere to the original research manual) and subsequent outcomes.

The area of research that investigates the challenges and outcomes associated with the transfer of research knowledge into clinical practice is known as translation research. There has been considerable research done in this area in other disciplines, however there has been little done in the field of speech pathology and virtually nothing in the area of stuttering. So let's talk about this in relation to the Lidcombe Program.

There is an extensive body of evidence in support of the Lidcombe Program. This evidence includes Phase I and II studies with medium and long-term follow-up, social validity data, randomised controlled clinical studies and clinical trials of the treatment in telehealth format. All of these trials have shown large effect sizes in terms of percentage reductions in stuttering. Impressive as these reports may be, this evidence has pretty well all been collected in strict research settings – this means highly-trained specialist clinicians and typically a restricted set of child inclusion criteria. It actually tells us little about the outcomes of the treatment in generalist community clinics.

This leads us to ask two quite different but equally important questions about Lidcombe Program outcomes: (1) Does the Lidcombe Program reduce stuttering under ideal research conditions? (2) Can the Lidcombe Program reduce stuttering

just as well in the general community? The terms efficacy and effectiveness relate to these two questions. Whether or not an intervention can work under optimal research conditions relates to its efficacy. If the conditions of a trial are optimised then it may be possible to detect even relatively small effects of the treatment. The Lidcombe Program has been shown to be efficacious under fairly ideal conditions.

On the other hand, the pragmatic question of whether an intervention works in routine clinical care relates to its effectiveness. In community clinics, the inclusion criteria for accepting clients into treatment are obviously far more relaxed, as SLTs basically accept whoever walks in the door with whatever associated problems they or their families bring with them. In such a trial, the question is whether the treatment is able to reduce stuttering in real-life non-ideal circumstances. And if not, why not? For the Lidcombe Program, these questions as yet remain unanswered apart from some data collected from retrospective file audits and surveys.

So, why is this effectiveness research so important? First, stuttering children need effective treatment to prevent the lifelong problems that we know are associated with chronic stuttering. There is evidence that the Lidcombe Program *can* reduce stuttering, so if those outcomes cannot be translated across the profession at large, then researchers and academics have a problem that they need to address.

Second, if barriers to implementing treatment in the manualised way in the community can be identified, then these barriers may be able to be addressed either by modifying the program, or by providing additional training for SLTs or perhaps by approaching service managers about delivery issues.

Third, if community SLTs are not routinely able to follow the manual, it needs to be known whether this lack of adherence really matters in terms of final outcomes. For example, does it make a difference if children are only seen once every two or three weeks instead of every week? And finally, if any significant predictors of outcome can be determined, then again the program may be able to be modified to take account of these or at the very least, advice may be given to parents about their child's prognosis.

So what is the bottom line here? We need information about what is happening out in community clinics and how the children are responding to treatment. In other words, we need a large-scale prospective study to establish the effectiveness of the Lidcombe Program in the general community. And guess what? The ASRC is currently conducting such a study in clinics across Australia, with children and SLTs also being recruited in the UK and Canada.

Participants in this trial are SLTs using the Lidcombe Program in public and private clinics and their young stuttering clients. There are no exclusion criteria for SLTs or their clients as we want a truly representative sample from the real world. Preliminary findings from the Australian cohort suggest that community SLTs who have received Lidcombe Program Consortium training frequently achieve outcomes for their clients similar to those obtained in clinical trials. If confirmed with the larger cohort this would be very good news indeed. We hope that the results of this study will lead to the development of a more efficient and effective treatment for early stuttering as well as providing information for SLTs and service managers about factors affecting outcomes in community clinics.



Dear Sue

I have been working with a little girl called Dorrie, age 4years 3months, who had a severe stutter, with an average of 23% SS, SR 8-9 in the beginning. The family has done really well and we are now down to 2s at home, and in the clinic it is sometimes a 1. We are all delighted with the progress but are finding it hard to get to 1s at home as every day there are tiny little stutters evident, nothing severe or even frequent, but enough to give a 2 for the daily Severity Rating. They tend to be repetitions of common words, mainly I (e.g. I-I-I want to do that) or 'cos' (e.g. 'cos-'cos-'cos- it's mine!). Neither the parents nor I wish to stop at this point even though we are so nearly there but I'm not sure how to prevent these last few repetitions. She is on unstructured treatment only but I wondered whether we should be 'targeting' the repetitions in a more formal way, or whether with time they will also fade away. This has gone on for about 4 weeks now and we all want to get to Stage 2 as soon as possible, as it has taken about 20 weeks to get to this current position. Can you advise me on how to proceed?

At this point in treatment, it is important that you continue to problem solve with the parent. In order to do this you need to ask some detailed questions about the stutter and stutter-free speech and about the way the parent is delivering the verbal contingencies (VC). These would include:

1. Do the residual stutters happen in groups or do they occur randomly? If the stutters happen in groups or patches, are these predictable in any way? For example, do they typically happen when child is more tired, or excited, or seeking attention?
2. How exactly are the verbal contingencies delivered? Are they spread across the day intermittently or are there conversations that are given higher numbers or "patches" of VC?
3. How many VC are delivered each day? When are they delivered (time of day, type of conversation)?
4. What types of VC are used? Are they varied? What words does the parent actually say for the VC?
5. Are the VC powerful? How does Dorrie respond to them?
6. What does the parent do when the child stutters? How does the child react to this?

Dependent on the answers to these questions and any others the clinician considers are important, the clinician will make recommendations. These could include:

- Try to do treatment at or just before a situation or time that would typically bring about stuttering. For example, if the child tends to stutter when describing her day to Daddy when he gets home from work, then increase the unstructured treatment just before Daddy is due home and deliver verbal contingencies when appropriate during the conversation.
- Teach the parent to look for periods of stutter-free speech across the day and to do treatment during unstructured conversations with Dorrie in these periods. This takes advantage of the times when Dorrie is naturally fluent and encourages generalisation. It also encourages the parent to be proactive about stutter-free speech rather than reactive to stuttered speech.
- Change the way the VC are delivered. If they are scattered randomly, try doing small patches of VC. Try to make them as unpredictable as possible.
- Change the frequency of the VC. Possibly they are too few to effect change or maybe they are too frequent and so have lost power or become predictable.
- Vary the time of day the VC are delivered. This helps to reduce predictability and to increase generalisation.
- Consider the conversations in which the VC are delivered. Are they similar or varied? Are they mostly during play, during recounts, during explanations? Are they delivered when Dorrie is excited and when she is calm, when she is tired and when she is bright and bouncy, when she is focused and when she is distracted? At this point in treatment the clinician needs to make sure that the VC are delivered across many different conversational conditions.
- Change the VC. After 20 weeks Dorrie might no longer be hearing them the same way she used to. Keep the VC as fresh as possible; pairing them with a reward system to keep them powerful may be of benefit. Some parents find it helpful to develop a list of the words actually used in the VC and some new alternatives that they could try.
- When possible ensure that the parent is using as many different types of VC as possible (praise, acknowledgement of stutters and stutter free speech, request for self evaluation, request for self correction).



Just explain that again...




? *I have just qualified as a speech and language therapist, and attended the Lidcombe training workshop which I found really interesting. While I understand the principles behind structuring the child's first sessions, why we do it and so forth, I am a little unconfident about exactly how to do this in the clinic. I wondered whether you could give me some tips about what to do? I know for example that 'sentence completion' is a good way to elicit shorter utterances, but could you give me some guidance about other ways of structuring a child's sessions, and some equipment suggestions? I am hoping to start the Lidcombe Program with my first client in a couple of weeks and he seems to be quite severe, so any suggestions would be really helpful!*




There are a number of ways to structure a conversation for the Lidcombe Program. Some of these are:

- The type of activity being used during a conversation. Some activities naturally elicit shorter utterances and these are more likely to be stutter-free. For example, playing a memory game or talking about a book with simple pictures.
- The linguistic elements of a conversation. The language used can be manipulated to elicit utterances which are of a length that is likely to be fluent. Some examples of how this might be manipulated are:
 - Modelling, sentence completion, binary choices, phonemic cues, commenting, pointing at a picture/something (and saying "Look..." and waiting for the child to make a comment).
 - Directing the conversation. As the child demonstrates increased fluency the amount of time the parent spends doing that can lessen. The aim of treatment during structured conversation is not to stay at the same level (e.g. all sentence completion responses) but to allow and elicit longer and more spontaneous responses from the child whilst continuing to be at a severity rating of 1 or 2.

- Activities used can be varied. Books, games, felt boards, puzzles, playdoh, drawing/colouring, magnetic boards, etc. are all useful. Some activities elicit fluent utterances for one child and not for others (e.g. some children become too quiet with playdoh).
- Books are often the easiest way to train a parent to implement structured conversations as they can see how to vary the structure within the conversation whilst keeping the child as fluent as possible. While this may be true, it is important not to stay with only one activity for too long as that activity might become discriminative stimuli. Try to vary activities as much as possible.

 *I am working with a little boy who I am beginning to realise has a clutter as well as a stutter. In your experience have you found the Lidcombe Program to be as effective when a child has both disorders present, and can I expect him to go down to 1s and 2s in the same way as a child with just a stutter ?*


 To my knowledge there has been no research about treating children who clutter using the Lidcombe Program. In fact, cluttering is often not diagnosed until a child is beyond the preschool years (St. Louis et al 2007). For these reasons much of what I say here is based on clinical observations rather than on published evidence.

If a child has a clutter as well as a stutter there may be a variety of impacting factors to consider including language or learning disorder, a fast speech rate, compromised intelligibility, and poor self evaluation. I would suggest treating the stuttering first, as you would with the Lidcombe Program, but ensure that verbal contingencies are only applied to effortless, stutter-free and intelligible speech. If the stutter is successfully treated but the cluttering behaviours remain, they may need to be treated separately.

It is difficult to predict what will happen in the case of this little boy. The most logical course to undertake would be to treat this child as a single case study. Take very careful measurements prior to and during treatment. Base your clinical decisions on these measures. Seek supervision opportunities and problem-solve this unusual case with senior staff or mentors.

Finally, consider writing up this case study for others to learn from your experience of treating a preschool age child who clutters.

Reference: St. Louis, K. O., Myers, F. L., Bakker, K. & Raphael L. J. (2007). Understanding and treating cluttering. In Conture E. G. & Curlee R. F. (Eds.), *Stuttering and related disorders of fluency* (3rd ed.) (pp. 297-322). New York: Thieme.

 *I have just been on a Lidcombe Training workshop and been introduced to the idea of Severity Ratings. I can see how very useful they are, and how essential to the running of the programme, but the problem is I am not very good at them! I was always one or two points different from the main body of the other participants. Have you any tips for how I might improve my skills as I realise it is vital I get this right.*



Consider the following to improve your skills in assigning severity ratings:

- If you are one point off then it is still considered reliable, particularly if you are consistent with how you assign your ratings. For example, if you are always 1 higher than others then that is OK.
- Consider the frequency and type of stuttering in the speech sample. If the client is experiencing more significant stuttering (e.g. many blocks) then this will be rated on the scale more highly.
- Remember that a SR 10 is the most severe stuttering anyone can experience (not just the most severe stuttering for the client in front of you).
- Listen to recordings of clients stuttering and practise giving a rating. Watch samples of stuttering with an experienced clinician, identify individual moments of stuttering and assign, compare and discuss severity ratings. More practice and more exposure will make it a bit clearer.
- Get the parents opinion of the child's severity in the clinic first and then make a decision about what severity rating you would give.

Our very grateful thanks go to Stacey Sheedy, Wendy Lloyd, Verity MacMillan, Mary Erian and Sally Nicoll for their very full and considered responses to this edition's Dear Sue and Just Explain That Again ..

The Lidcombe Program in the Community

Rosemarie Hayhow

(Additional comments about the study in Canada from Rosalee Shenker)

When we began to run this study in England we were able to find Speech and Language Therapists (SLTs) who were willing to sign up, but the recruitment of children was slower and in the end fell short of anticipated numbers. This was as true for Canada as it was for the UK, where only around 10% of the Speech-Language Pathologists (SLPs) who expressed a willingness to join the study were in fact able to participate. The most important point to start with is our appreciation of the openness of the therapists who have recruited parents, and their willingness to take on the extra work. All of the SLTs conducting Lidcombe Program research have worked as clinicians and we are familiar with the pressures and competing demands of clinical life. In our clinical research role we are also acutely aware of the need for evidence to support not just clinical decisions but also the value of SLTs. We need to be able to show that we can make a real difference to children's lives and that we are good value for money. Commissioners may enjoy anecdotes about successful treatments but their decisions are based on research evidence. Sue O'Brian has set out why we need to study the effectiveness of the Lidcombe Program, and SLTs, Ethics Committees and Research & Development (R&D) departments would agree with the issues she identifies. In practice, however, there are obstacles to this process and we will identify some that we have experienced in the UK and Canadian arms of the study.

Many of the challenges facing a research team in getting effectiveness studies up and running are as a result of the procedures and processes being tailored to safeguard both participants and NHS Trusts during drug trials. Some of the issues are rather convoluted and so I will describe just a few of the hurdles faced when widening the scope of a study from Australia to the UK.

Key players in research governance:

Research Ethics Committees (REC) primary role is to protect participants, and a research study cannot proceed until it has been passed by the researchers' local committee. The committee considers the risks to participants and also risks that may impede the study, so they look at research methodology, procedures, recruitment and outcome. When the study has been approved it can run anywhere in England provided there is local agreement. The Principal Investigator has a legal obligation to ensure that the study runs according to the Protocol and if any changes are required, no matter how small, these must be passed by the REC before they can be implemented.

Research and Design (R&D) departments are responsible for ensuring that any research that takes place within their NHS Trust will not lead to any problems and that local issues are addressed. R&D officers will also need approval from the data protection guardian. When a study recruits participants from a number of NHS Trusts then each Trust must agree to the study.

Our local **ethics committee** has some understanding of SLT research and how it differs from medical research. In part this is due to one of the Bristol Speech & Language Therapy Research Unit directors sitting on the committee for some years. However, the need to conform to national protocols can clash with the needs of our client groups. A couple of specific examples may illuminate some of the issues researchers face:

1. The Participant Information Sheets: An effectiveness study needs to record treatment details with as wide a range of mothers and children as possible. We do not want to exclude parents who are either financially or educationally disadvantaged, yet the requirements with regard to patient information sheets are such that even experienced readers may be put off by the length and complexity of the documents. There is also guidance concerning the content of these information sheets which amounts to about three sides of A4. This is fine when the risks to the individual patient are high, and ensures that potential participants fully understand their rights and any risks they might incur. In studies like this one however, there are minimal risks to participating parents and children. Nothing about their treatment changes and the safety mechanisms, procedures etc. that we have as practicing SLTs are all in place. So the Participant Information Sheets send a confusing message.
2. Speech samples:
 - a) It may be the word *sample* that rings alarm bells i.e. that we are keeping a *part* of the participants. There have not been enough discussions with ethics committees and data protection personnel for them to understand issues specific to our speech data, and our methods of recording, storage and analysis.
 - b) Transfer and data protection. Concerns are raised about speech samples and confidentiality and yet we know that it is almost impossible to identify an individual, especially an individual child, on the basis of the short recording made while they look at a book or engage in everyday conversation. A further difficulty with speech samples relates to IT departments' control over what therapists can put into their work computers. Many SLTs use computers that are set up so that memory sticks or similar devices cannot be connected. Just at the time when neat and cheap digital recorders that plug straight into the computer offer opportunities for really good pre, post and during treatment speech samples, SLTs find that they are unable to store them because of their IT department's rules. When clinicians and researchers work together there can also be problems with transferring samples. NHS net automatically blocks any MP3 files. Of course there are ways of working around these problems but it takes time and adds to the frustration of trying to use modern technology, in a time efficient way, to support clinical and research work.

R&D departments are encouraged to take a proportional approach so that they can be very thorough with any high risk studies and not waste resources on those of low risk. I had not realised until recently that the way the community study was set up presented as high risk from the R&D point of view. We have one researcher in the UK -myself- and then there are the SLTs who aim to recruit parent/child participants

at the appointment when the LP is agreed as the best treatment option for them. The lack of a local researcher i.e. one in each participating Trust, is a concern to R&D departments because they have no one in their Trust who is actually responsible for ensuring that the study is run according to protocol, and that Good Clinical Practice (GCP) guidelines are followed. Somewhat confusingly, GCP refers to research practice, and research active staff have to attend regular training events. Some R&D officers refuse to allow a study to run without a local researcher who has also completed GCP training. To implement this would mean extra work and responsibility for the participating SLT, something which is unsustainable in the current climate of cuts and down-gradings, and seems excessive when maybe only 3-6 children are recruited.

In Canada some of the same difficulties with regard to obtaining approval from individual sites were also experienced. Despite offers of help from Sue O'Brian (who was co-ordinating the study from Australia) to develop individual ethics documents for each potential site it was finally agreed that this would be too time consuming if the end result turned out to be just one client. Recruitment therefore was made from private practice where the informed consent of the parent was deemed sufficient for the study.

Feedback from SLTs.

During the recruitment phase of the study pressure on many SLT departments increased, with reorganisations, staff reductions and so on, which affected the numbers of children they were able to recruit:

1. Work pressure meant some therapists found they hadn't the time to recruit parents during the already rushed initial sessions. This was especially the case with parents who were less used to working in partnership with professionals and where the LP procedures were not part of their usual parenting procedures.
2. Parents came with their own anxieties, and their agenda did not usually include joining a research study. One SLT expressed this saying that if she could invite parents once therapy was underway she would have had many more recruits. Once the initial parental anxiety is replaced by feelings of empowerment, she felt parents might feel more inclined to sign up. This raises questions about research methodology, and the payoff between best research design versus higher and more representative recruitment.
3. Caseload pressure meant that in some recruited departments the LP became a final resort i.e. it was only used when all else had failed. This not only affected the number of potential recruits but also biased the sample.

North American SLPs also expressed the same concerns, in particular the second point about parents often being too anxious about their child during the initial appointment time to take in anything else. The reluctance of the SLPs to bring up the research study is seen as rightly implementing best clinical practice over the needs for clinical research. Currently there are 18 participating SLPs but while there were hopes of recruiting 20 subjects, currently only 9 have been forthcoming.

I work with colleagues who recruit from cases with other communication problems and low recruitment numbers are a big issue for them also. We have a great deal of work to do before we can run efficacy and effectiveness studies with the relative ease that some of our medical colleagues enjoy. It is work that we can and must do if we are to demonstrate to commissioners that we are worth employing, and every study that is undertaken should inform the next one in order that we may achieve well designed research studies that are workable in clinical contexts. Practicing SLTs have such an important role to play and, if I generalise from the parents I've spoken to when contacting them for their 9month follow-up, there are parents who want to play their part as well. Some seem flattered by having been asked to join the study as they had never thought they could contribute to research. They also want to do their bit to ensure that children and parents can have therapy in the future. As for me, I have the pleasure of listening to these parents chatting with their children as I record them over the phone, something which helps to remind me of why I'm doing research and ultimately who it is for.