

NEWSLETTER

Welcome to the second newsletter for our communication development research. The study is going well and over 90 children have now joined. This newsletter tells you a bit about the children who are taking part, what we have learned so far, some of the questions that have arisen from the study and how these questions might be answered.

What is the research for?

The study your child is taking part in will answer two key questions:



- Which children with motor disorders will have communication problems?
- How severe will children's communication difficulties be?

The results of the study will help doctors and therapists to give advice to parents about how their child's communication is likely to develop. The study will also help speech and language therapists develop individualised therapy programmes early in children's lives.

Who is taking part?

Our study involves children with non-progressive motor disorders who are 2-5 years old. All the children have some difficulty with communication, which can range from a very minor delay to very severe problems producing vocalisation and speech. Children usually join the research at 2 or 3 years of age. We see the children for the study once when they are 2, once when they are 3 and once when they are 5. We aim to see 120 children. Children in the study come from Cumbria,

Northumberland, Tyne & Wear, Teesside, County Durham and Cleveland. So far, 95 children have joined the study. All have been seen at least once, 40 children have been seen twice and 3 have been seen three times. As we are only about half way through the study we can't yet tell what predicts communication ability but the research has already shown some important relationships.

Motor skills, vision, hearing and seizures

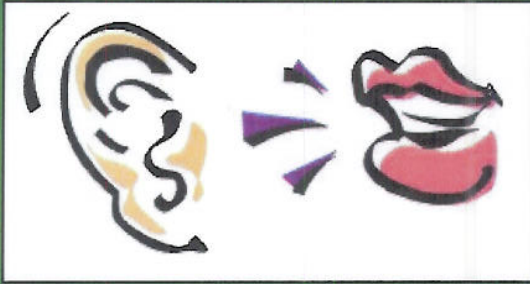


As we hoped when we set up the study, the children who are taking part have wide ranging skills and abilities. Most children in the group need help with mobility and most have difficulties using their hands and manipulating objects, about half of the group have severe restrictions in the range and type of objects they can handle. Two thirds of the group have visual problems. Both motor and visual difficulties will make it harder for children to learn about the world and may slow down their communication and language development. About a half of the group have epilepsy. Very few children have hearing difficulties.



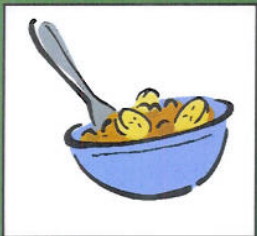
Communication

At two years of age 10% of children in the study communicate primarily by moving their bodies, for example to show that they are enjoying activities or to indicate displeasure. Around 80% of the children can attract their parents' attention or ask for objects by reaching or moving towards objects/people. About 85% can vocalise and about half of the group have some spoken words that their parents recognise. About 15% use communication aids, such as picture charts or electronic devices with speech output.



At Newcastle we have developed a speech and language therapy for children who speak, but whose speech is affected their motor disorder and is difficult to understand. We have tried the therapy with two small groups of children (one primary and one secondary school age). On average the percentage of words spoken by the children that were understood correctly increased by around 15%. Teachers also reported that children communicated more clearly at school. We are now developing a large trial of the therapy in England and Scotland. The application will take about 12 months to prepare - we'll update you in future newsletters.

Eating and drinking

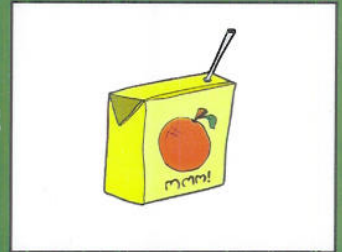


In the study we are asking about how children are fed to test if severity of chewing and swallowing difficulties might be associated with speech development. It would seem logical that there is a

link between eating/drinking and speaking as we use some of the same muscles for both activities. But, the movements for the two activities are different and are controlled by different signals from our nervous system. As yet there is no research to suggest that we can predict children's

ability to speak from their eating/drinking skills and vice versa.

In our study around two thirds of children have difficulties chewing 20% are fed via tubes, either to supplement or replace oral feeding.

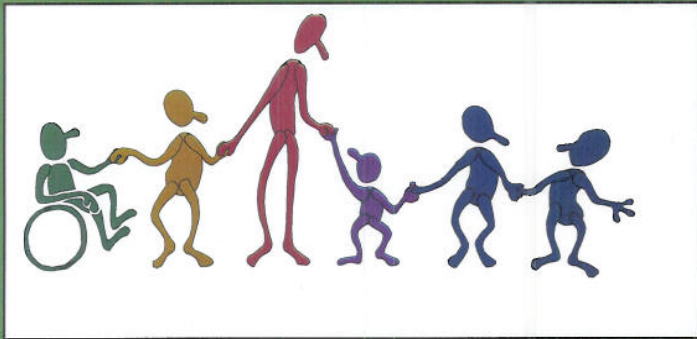


Most of the children who are tube fed have had a gastrostomy, so that food can be passed directly into the stomach. We know from talking to you and other parents whose children have feeding difficulties that it is hugely important to get decisions about how to feed children right. Investigations for feeding difficulties can be fraught and all options need to be carefully considered. We are starting a programme of research to find out what influences parents' and clinicians' opinions about different feeding options for children with severe eating and drinking difficulties. We also aim to develop information materials such as leaflets and video/DVDs for parents. We will be discussing this research at the next Parent Steering Group (see below). Please contact us if you'd like to know more.

Drooling

Drooling/dribbling can be a really big issue, especially for older children. Drooling affects around 60% of children in the study. 50% of parents report that drooling is frequent/constant and drooling is severe (with clothing becoming damp) for 40% of the group. Some of the children in the study use bibs and bandanas and some have been prescribed medication to reduce their drooling. At the moment there is no research to show which type of medication works best and a Newcastle team led by Dr Jeremy Parr is applying for funding to compare two different medications. We will be discussing the planned research at our next Parent Steering Group (see below) and will keep you updated in future newsletters.

Parent Steering Group



A group of parents meet with the researchers twice a year to discuss research projects. The group helps to decide which areas are highest priorities for research, what specific questions should be asked and how research should be conducted. The group also discusses how the research is progressing and suggests changes and solutions to problems if they arise. We really value the input parents give. Your advice helps to make sure that we are asking the right questions and are collecting the right information in way that is acceptable for families.

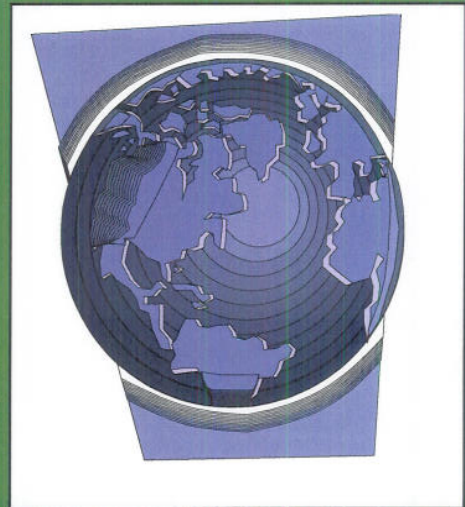
In previous meetings we have talked about the research investigating the intervention to improve children's speech. This helped us decide which groups of children and staff should be involved. We also decided on which questionnaires to use and how to ask parents and teachers the right questions to measure whether therapy had been successful.

At the next meeting we will be talking about the next stage of the speech research, the studies to find the best way to reduce drooling and the new research to help make decisions about the best method of feeding children with eating and drinking problems. The meeting will take place at 10.00-12.30 on Friday 14th October in the Sir James Spence Institute at the Royal Victoria Infirmary (lunch and travelling expenses will be provided).

All parents are welcome - the more advice we get the better the research will be!

If you are interesting in coming along and would like to talk to someone who has been please email Johanna Smith at johannasmith1@hotmail.com. If you'd like to book a place please email Lindsay Pennington at lindsay.pennington@ncl.ac.uk.

Research in other countries



This research we are doing on communication development is one of only two studies that is taking place across the world. The other study is based at Wisconsin in USA. The leaders of the two research programmes, Dr Katie Hustad in Wisconsin and Dr Lindsay Pennington here in Newcastle, are working together to make sure that information on communication development from the two studies can be compared.

Looking at both groups of children will allow us to explore development in specific groups of children which may be small in any one country (such as, those with visual impairments).

Thank you!



Thank you very much for your help with this research. We know that life is very busy for all families who are taking part and we really appreciate the time you give to help us. We hope that the study will be a very valuable resource to families, clinicians and researchers in the future. By working together with a large number of families we can find answers to questions about communication and give more advice to parents in the future about how their child's communication is likely to develop. If you have questions you would like us to try to answer in the study please do let us know - the more we ask, the more we find out.

Know anyone else who would like to join?

We are currently working with physiotherapists, speech and language therapists and paediatricians to recruit more children to the study. If you know of other parents who may like to join the study please pass on information to them or ask them to contact us.



Who do I contact about the study?

If you would like more information about the study please contact:

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