

## **RDS Advice Work Case Study: Systemising the management of eating and drinking for children with Cerebral Palsy and brain injury**

This case explores RDS's (Research Design Service South East) advisory support for a research project that successfully won a 3-year grant from Research for Patient Benefit. It is now at the halfway point in the research project.

This case study illustrates a number of very useful insights for the would-be researcher, research grant applicant and the research adviser or research and development department. These points are:

- Relatively inexperienced researchers can win research grants if they have a good idea and they work at it. You don't have to have been a Principal Investigator to win an RfPB<sup>1</sup> grant.
- Also to get a research project funded and off the ground you do not have to be an academic with peer-reviewed research cachet or a medic.
- This research project is clinically-led and driven by allied health practitioners
- Time release amongst health professionals for 'seeding knowledge' and research about research makes all the difference to the chances of a project getting on track and having a chance of being funded

### **The Project:**

Speech and Language Therapists at [Chailey Heritage Clinical Services](#) traditionally take responsibility for assessing, managing and treating the different kinds of eating and drinking difficulties that typically occur in a population of children and young people with complex physical disability, including Cerebral Palsy (CP). Diane Sellers, a very experienced speech and language therapist, worked as a member of the multi-professional Nutrition Team. This expert group identified several unanswered clinical questions in their field. The pivotal question for them was: why is there not an agreed, simple and universal rating scale to indicate the extent to which an individual's eating and drinking ability was affected by limitations to oral skills. Oral skills include the ability to bite, chew, suck, swallow and retain food and fluid in the mouth.

Several assessment tools for eating and drinking were available for use by speech and language therapists, but none provide a rating scale of eating and drinking difficulty with the potential to be used by parents, in consultation with professionals knowledgeable about eating and drinking.

There were glaring gaps in the literature on the topic. Clinicians, parents and carers talked about the problems but the expert community did not have a tool to readily classify, grade and guide people through this issue. Diane proposed that the development of a classification system would make a significant difference to

---

<sup>11</sup> RfPB The Research for Patient Benefit programme is one of the funding streams for health research run by the National Institute for Health Research or NIHR

outcomes for these children and young people. It could be based on a similar system that rates gross motor function in children with cerebral palsy.

In the first instance, Diane was given a small amount of time release to do the preliminary, exploratory research and, at least, establish if there was a gap in clinical knowledge and practice. The first stage was all about 'researching the research'. This identified a gap that needed filling.

*"Currently there is no agreement about how to rate the severity of a child's eating and drinking difficulty, i.e. the child's ability to move muscles to bite, chew and swallow. The words "severe", "moderate", and "mild" are all used without an agreed definition. For some researchers, a "severe" difficulty is when a child cannot feed themselves. Others have mistakenly assumed that only children with more severe general movement difficulties have problems with eating and drinking".*

(Extract from study descriptor 2010, Chailey Heritage Clinical Services, 2010)

Diane and colleagues at Sussex Community NHS Trust pursued the project when it was at first 'a very thin weed of an idea' as Diane puts it. They approached RDS for help.

### **The advice input from RDS:**

Terry Pountney from the Research and Development team at the Sussex Community NHS trust referred Diane to the RDS. Over an intensive 6 month period, plus support time before and after, Claire Rosten and Natalie Lambert provided advice to Diane and her emerging, investigative team.

*'RDS helped me to step up to the mark. I found Claire to be very rigorous in questioning me about the project and my plans to investigate it. This helped me sharpen the research question, identify gaps in my understanding and develop a persuasive research proposal'*

RDS helped the researcher and the clinical unit to:

- Formulate the research question and the methodological plan for answering it
- Build the researcher team and recruit the necessary expertise plus the cross-disciplinary advice required
- Build up statistical and qualitative rigour with the most appropriate and effective research plans
- Identify the potential funding source/s
- Write a quality research bid
- Involve patients and the public – the proposal was put to 'lay people' plus the idea tried out on them prior to submission
- Testing with other clinicians - speech and language therapists in this case

The application to Research for Patient Benefit was a success and is now well underway. The first stage of the project was to develop a draft classification system from the literature, from assessments, and from clinical experience.

### **Research Method Feature: NGT Nominal Group Technique**

NGT is a formative evaluation technique frequently used in building consensus. It is both a qualitative and a quantitative method. Typically it involves generating ideas; sharing and clarifying ideas; and voting between members of the 'community' on the agreed priorities. It has the advantage of inclusivity. All contributions are involved, rated and ranked without the potential disadvantages of group and inter-group processes. NGT has been used for many studies in the health arena, from prioritising after care for stroke patients and patient identified outcomes in mental health, through to community evaluation of the relative effects of health conditions and designing training for radiographers.

NGT can be used for evaluating ideas and practices especially where there are perceived barriers to evidence-uptake, or inconsistent use of evidence. This is the case here. We find that the best evidence about techniques to help children in eating and drinking are not adequately shared, understood, deployed and evaluated.

### **How this evaluation study works:**

Diane and the RDS utilised the Nominal Group Technique approach to present the draft classification system, now called EDACS (Eating and Drinking Ability Classification System). This has been presented to a series of expert professionals, parents and individuals with cerebral palsy.

*Parents and clinicians have enormous insight into tackling this issue and we wanted to deploy a method that captured the 'wisdom of the crowd'.*

At the end of every group, participants voted for the changes they would like to see to EDACS. At least the top five changes were implemented to EDACS which was then presented to the next group. This continued until no new issues were raised. It was important then to present EDACS to a wider international expert audience, for close examination of the content of the system.

The decision was taken to use a Delphi Survey approach to facilitate the collection of both qualitative and quantitative data. Ninety five participants have taken the opportunity to provide comments and suggestions for change as well as indicate the extent to which they agreed with the content of the EDACS. At the end of the first Round of the Delphi, more than 80% of participants agreed with 39 out of the 42 statements which represented the content of EDACS. Further revisions were made to EDACS which was then sent back out to the same group of participants with a

new survey. More than 80% of participants in Round 2 have agreed with the five new statements which represented the revised content of EDACS. The project is now moving in to the fourth and final stage.

The initial plan made with RDS was to test the inter-rater reliability of the proposed system by comparing the ratings of individuals' eating and drinking abilities by pairs of different Speech and Language therapists. In the course of the development of EDACS, it has become apparent that it is also important to compare speech and language therapist assigned levels to those levels assigned by parents to their own child. The RDS has provided comments on the proposed new method and statistical analysis.

RDS provides consistent input by holding regular research 'surgery' sessions with the team.

The project is going very well and has had an influential presentation made to the expert community of which it is a part. Presentation of the project was made at the European Academy of Childhood Disability annual conference in May 2012:

This is the abstract of the work so far in *Developmental Medicine and Child Neurology* May 2012 Vol 54 Supplement 3 p8.

<http://onlinelibrary.wiley.com/doi/10.1111/j.1469-8749.2012.04297.x/pdf>

*Jim Simpson*

Jim Simpson Consultancy, summer 2012

[www.jimsimpsonconsultancy.co.uk](http://www.jimsimpsonconsultancy.co.uk)