How can we help develop the evidence base in paediatric neurodisability?

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There is a need for more capacity for high-quality research in paediatric neurodisability. All clinicians want to know which interventions work and, just as importantly, which do not work for children and families. We also need to know more about best methods of assessment and service provision to meet the needs of disabled children and their families.

Increasing importance is being attached to research findings in the planning of services, but studies are rightly required to be of high quality and to answer the central questions rather than concluding more or bigger or better studies are needed. Small, inadequately powered studies, however much passion and effort has gone into them, are a lost opportunity as they do not contribute to the evidence base.

The British Academy of Childhood Disability (BACD) is a multidisciplinary organization for professionals working in the field of childhood disability which aims to promote professional links, service development and research. It is affiliated to the European Academy of Childhood Disability. The BACD’s Strategic Research Group has recently posted on the research pages of its website information about the current research environment in the UK. If terms such as National Institute for Health Research, Comprehensive Local Research Network, Portfolio Study and IRAS do not mean much to you, then this may be the site for you.

We wrote the content of the site to outline how aspiring academics and busy clinicians can become more involved in research. The aspiring researcher is not likely to have the experience to mount a major grant application. The new BACD website is designed to guide potential researchers in the right direction. The website includes opportunities for junior and senior researchers for fellowships and project funding. Also, in a partnership between BACD and Warwick University, UK, all current funding opportunities relevant to neurodisability research are flagged; the information is updated each month. One of the site’s important recommendations is that aspiring researchers should consider aligning themselves with a programme of research being undertaken by a group which is led by experienced researchers. This way, even a small piece of work can contribute to a wider programme. Furthermore, the aspiring researcher will observe good research practice and will learn how to convert a research idea into a valuable study. His or her supervisors will be up to date with funding streams for fellowships or grants, should the aspiring researcher’s career so develop.

Busy clinicians may have little experience or time for research; how may they help if they are not able to start a project themselves? The Strategic Research Group wants to encourage multi-centre studies designed to answer clear questions in suitably powered trials. Paediatric neurodisability is a complex field with complex research questions; some conditions are uncommon, and in other conditions the
variability of children’s neurodevelopmental difficulties can make recruitment difficult – for example, how would you recruit 20 teenagers that have both cerebral palsy and autism? As the Canadian CanChild has shown it is possible, we want to encourage clinicians to take part in research through a clinical network of recruiting sites. The UK MENDS study of melatonin for sleep problems has taught us that a network of neurodevelopment teams can support high-quality research by recruiting patients to a trial. Recently, a number of UK sites have volunteered to recruit to a proposed study on the management of drooling in children with neurodisability.

In the UK, the budget for the National Institute of Health Research (the research arm of the NHS) has not been cut in the recent Government-spending review; indeed, there is good news in that it increases slightly over the next 3 years. This is a strong endorsement of the importance of research about patients and services. Those of us working in childhood disability must take advantage of this opportunity and the website of the BACD is one attempt to encourage this. Visiting the site could be your next step in taking part in quality research into the treatments and services disabled children, young people and their families need.

Other countries will be developing strategic approaches to paediatric neurodisability research. European Academy of Childhood Disability might be able to compile information about European funding streams, training networks, scholarships and specific calls around childhood disability. A number of European calls fund collaborative activities around research. One such activity, RICHE, is in the start-up phase of establishing a child health research platform funded by Health Research Framework 7 of the European Union.

**Conflicts of interest**

Allan Colver is Chair of the Strategic Research Group of the British Academy of Childhood Disability.