Cerebral Visual Impairment project meeting

12/01/2015 Veysey Building

Family Faculty: Ellen, Kirsty, Julia, Trisha, Anna-Louise, Lucie, Sally, Jane, Cindy, Antony, Sarah

PenCRU: Sharon, Katharine, Chris

Other colleagues and visitors: Cathy Williams (Bristol University)

Apologies: Tracy, Sharon, Kate, Bobbie (Family Faculty)

Overview

In this meeting:

- Cathy described her proposed research into cerebral visual impairment (CVI)
- We discussed parent experiences in relation to their child's visual impairment and whether the research would address the concerns parents raised.
- We discussed the proposed method for the research, including the measuring tool and which outcomes would be important to measure.

The proposed research

- Cathy is currently writing a funding application to undertake research into both the prevalence of CVI and an intervention to support children with CVI in mainstream primary schools.

- The first study will try to estimate the number of children who may have CVI (prevalence) by asking parents and teachers of children in reception, year 1 and year 2 of primary schools to complete Strengths and Difficulties Questionnaire (SDQ) and for the schools to report the number of children who have Education Health Care plans. Assessments for CVI at a clinic will then be offered to all children who are thought to be at risk of having CVI and 10% who are thought not to. This 3-step approach also aims to provide useful information about which assessment is most likely to pick up children with CVI.

- The second study is a feasibility study (small-scale randomised controlled trial). A number of primary schools will be recruited and split into two groups. One of the groups of schools (the experimental group) will take part in a new intervention to support children with CVI. This will involve the school working in partnership with eye doctors who will hold special clinics for the children with CVI attending the school and advise school staff on cost-effective strategies to support children with CVI within the school environment. The other group of schools (the control group) will carry on as usual without any intervention re CVI.

Discussion points:

Needs of children with CVI

- Parent carers reported that CVI can often be undiagnosed and that there is a lack of awareness of CVI both with parents and with professionals. Behaviour/learning needs are often seen as a

cognitive issue but not related to visual processing. Children with communication needs may not be able to express what they can or cannot see.

- This lack of awareness may be impacted by a lack of agreed terminology. Cathy explained that cortical visual impairment tends to describe impairment in eyesight (acuity) while cerebral visual impairment will include sight impairment but more widely includes impairment anywhere in the brain which can impact interpreting or processing visual information. Children can have good field of vision but still have CVI.

- This lack of awareness and agreed terminology can mean parents see their child's behaviour is different but cannot explain it. The child's behaviour is blamed rather than the lack of support or understanding about CVI.

- Problems with visual processing were discussed as being a significant barrier to learning. A comparison was made to the recognised link between behaviour and communication needs. It was suggested that introducing visual aids had the potential to substantially change disabled children's lives in the same way communication aids such as Makaton and talking mats had.

- Consistency in the person undertaking the testing of CVI was seen as critical by the attendees, as their experience showed them that their children would have different test results based on their familiarity, comfort levels of the process and whether they were tired/hungry, time of day of the assessment.

- Parent carers felt that when children are assessed, this is not always holistic. The interlinked nature of problems was not always recognised. Visual problems can often be at the bottom of the list of priorities for professionals working with disabled children. They are often unable to access support for the visual impairment as services tackle other problems or one problem at a time. Physiotherapy and speech and language services are often provided but visual support services are not as common.

- It was suggested that if CVI was better supported, children would be able to do more for themselves (unlock their potential). Attendees described how simple and small the changes needed to be to support CVI; one explained that her child needed to have their wheelchair positioned at a slight angle rather than facing the object of interest (eg whiteboard) as her field of vision was slightly behind. Another explained that finding a way to help her daughter know which end of the spoon was which, would transform her ability to eat. Another attendee explained that having verbal explanations for pictures helps a lot as does large text in busy environments.

- Attendees reported that they had been hopeful that changes to the SEND process brought in last year would have helped – but joined up services (health, education and social care) and the opportunity to buy in services themselves, hadn't materialised. Concern was also raised that support in school doesn't always carry forward when children move classrooms/get new teachers and teaching assistants.

- A lack of money and resources was seen as a key obstacle to providing the specialist support that children with CVI need. Parent carers described inequitable access to support. Some had received excellent support from vision impairment teachers within their child's schools and the expertise of a local school (WESC) and their outreach service was recognised. As was the guidance provided by Christine Roman whose contact details are provided at the end.

- Others reported that their child's schools hadn't seen a need for visual impairment expertise. Attendees reported that raising awareness within special schools is as important as in

mainstream schools as they may not be informed about CVI and sensory loss can be missed. Ability to thrive is limited by lack of knowledge.

- Parent carers need evidence to support their applications for assessment and funding. This research was recognised as important to address this gap.

Proposed method for the research

- Parent carers queried if the research should be focused on mainstream when the largest prevalence is likely to be in special schools. Cathy explained that the research is currently focused on children who aren't receiving support for visual impairment but acknowledged not to assume that children in special schools were receiving support. Cathy plans to explore involving a special school in her sample.

- Attendees thought that the information being made available to parents about the study was going to be critical. As the SDQ contains personal questions, clear information about the purpose and reason for the research was needed in any covering letter to encourage participation. It was suggested that many parents without special needs children may not understand why they are being asked to take part. Emphasis on the hidden nature of CVI needed to be included.

- Attendees suggested that getting parents and school governors onside was crucial when approaching schools to take part. Attending a school assembly which parents would be at, along with a parent to explain the research was recommended, as was an advert in the Primary Times magazine (sent to all parents).

- It was also recommended to carefully select the time of year to approach and run the research in schools (eg avoid time when schools are busy writing reports).

- The age range (reception to year 2) was queried. As schools may not have yet discussed any behavioural issues with parents of children in reception yet; undertaking the research and asking parents of children in reception to complete the SDQ may be insensitive.

- Cathy explained that the outcomes from the studies would be both individual (has the child experienced any change) and wider impacts for the school (staff and practices being more informed).

- As CVI can be difficult to diagnose with just a vision test, attendees felt it was important to measure behaviour as well. The proposed SDQ is a standardised tool used to measure behaviour and would be useful to show quality of life measures which the attendees felt were important outcomes such as whether the children are happier, could concentrate more and had better interactions.

- Some attendees felt that the SDQ was too long and too focused negatively on behavioural issues rather than strengths. A concern was raised as to whether it would pick up children who are coping within schools. Cathy suggested an alternative would be to ask the key five questions, Dutton (expert in CVI) found to identify visual processing problems.

- It was suggested that in addition to the SDQ, parents could choose to add outcomes that they would like to see for their individual child. Measures that would show whether their child has improved; such as being better able to eat or moving less/finding sitting still easier.

- Cathy described the International Classification of Functioning (ICF) and suggested it may be useful to code outcomes in line with this and through this work out the key top ten outcomes to

trial (eg level of participation). It was suggested that the SDQ may be answerable in relation to children attending mainstream but ICF may be more appropriate for children attending special schools.

- Parent carers queried the process for children who are picked up at risk of CVI but not in the experimental group, and the process for children if the SDQ revealed any other possible conditions such as autism or ADHD. Cathy to ensure processes are in place before research starts.

Next steps:

- Cathy will be submitting her application later this month – the discussion from this meeting will be incorporated into the funding application.

- Cathy will stay in touch with PenCRU and if the project is funded, we will look to arrange further opportunities for Family Faculty members to be involved in shaping the research.

- If the funding application is not successful, Cathy will look to amend the proposal and apply to different funding sources.

- PenCRU to find out more about WESC work re CVI and to keep Family Faculty informed if there are any local events they may be able to attend.

Signposting:

- Christine Roman www.cviresources.com
- LittleBearSees http://www.littlebearsees.org/
- MoorVision http://www.moorvision.org/
- WESC http://wescfoundation.ac.uk/