In this article Ian describes the partnership project which produced the guidance for practitioners. Ian was Project Leader. The article is based on material previously available on the website of the Royal National Institute of Blind People (RNIB). The guidance for practitioners which was published in 2011 by RNIB as a CD-ROM Resource Pack has sold out. However, the material is now available on-line at http://www.rnib.org.uk/professionals/education/support/resources/autism/Pages/visual-impairment-autism.aspx.

The article is available as a pdf at http://ianpbell.com/visual-impairment-autism/.

Please refer to this article by acknowledging the author, providing the web address and noting the date that you accessed the article.

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This is a revised version of the article originally posted in September 2012
The background to the Project
The need for the Visual Impairment and Autism Project became apparent when RNIB received requests for advice about meeting the needs of children who had both visual impairment and autism. These requests came both from practitioners and parents. At the time, there was insufficient knowledge to give advice. It was clear that there was an urgent need to obtain information about the strategies that can be used to support these children.

The Project partners
A partnership project was therefore established. RNIB was the lead partner and provided the funding. Some of this was generously provided by two trust funds; the remainder came from RNIB itself. The following provides brief details of the four partners, with links to their websites:

RNIB is the UK’s leading charity offering information, support and advice to over two million people with sight loss. rnib.org.uk

Brookfields Specialist SEN School is a West Berkshire day school for pupils with complex needs including autism and sensory impairment. brookfieldsschool.org

The National Autistic Society is the UK’s leading charity for people affected by autism. autism.org.uk

Sunfield, a UK charity, provides residential care, education and outreach support for children with severe and complex learning needs, many of whom have autism. sunfield.org.uk

The Project dates
The project ran from 1st September 2008 until 31st March 2011.
Knowledge and skills prior to the Project

Children who have both visual impairment (VI) and an autistic spectrum condition (ASC) are a very low incidence group. However,

- the combination of visual impairment and autism has a very high impact on the children concerned, on their families and on the practitioners who work with them
- the needs of these children tend to be poorly understood
- meeting those needs presents a considerable challenge to practitioners.

When the project was set up there were few publications which specifically addressed the needs of this group and that those which did exist were mostly not very comprehensive and lacked detail. Thus, individual practitioners were left to develop their own practice, which often appeared to rely on anecdotal reports from colleagues and on intuition.

However, anecdotes are often unhelpful, as they lack detail and fail to indicate why something has worked or failed to work. Furthermore, intuition is misleading when dealing with autism. In order to meet the needs of a child who has both visual impairment and autism, it is important to interpret that individual's behaviour. Doing so requires an understanding both autism and visual impairment.

Many practitioners working with visually impaired children have an excellent understanding of visual impairment. They can therefore interpret the behaviour of a child with visual impairment and autism from the visual impairment perspective. However, fewer such practitioners have experience of working with sighted autistic children, making it difficult for them to interpret the same child's behaviour from the autism perspective.

Prior to the project, it was not clear which approaches should be employed to support children who have both visual impairment and autism. Many approaches used for fully sighted children with autism rely heavily on vision; it was thus thought likely that they would be inappropriate for those with little or no sight. It also seemed possible that some strategies commonly used with visually impaired children would be inappropriate for those who also have autism.

Thus, the primary goal of the project was to provide guidance for practitioners working with children who have both visual impairment and autism.
Children with Visual Impairment and Autism

Children who have both visual impairment (VI) and autism vary markedly. The project was concerned with 2 very broad groups of children:

- those who have VI and who also have a diagnosis of an autism spectrum condition, including Asperger syndrome
- those who have VI who do not have a formal diagnosis of an autism spectrum condition, although their profile of skills and needs suggests that they may be on the autistic spectrum.

In both these groups, many of the children have a complex range of disabilities. For example, in addition to their visual impairment and autism (whether diagnosed or not), these may include:

- learning difficulties - which can vary from mild, through moderate and severe to profound
- physical disability - for example, cerebral palsy, which is frequently associated with visual impairment
- a hearing loss
- attention deficit hyperactivity disorder (ADHD)
- dyspraxia
- dyslexia
- epilepsy
- other chronic medical conditions.

The Project team

Work on the project started in the summer of 2006, when a steering group was formed. The group designed the project and put together a funding bid. It was composed of representatives of each of the partner organisations and met periodically to provide a discussion forum and to guide the project.

For most of the duration of the project the members of the steering group were:

- **Catherine Bernie**, Autism Lead, Autism and Behavioural Support Service, Brookfields School
- **Jane Headland**, Headteacher, Brookfields School
John Byrne, Headteacher of Brookfields School until Easter 2009, Francine Griffith, previously Head of Education at Sunfield, and Dr Trevor Stevens, previously Autism Lead at Brookfields School, played a crucial part in the project in its early stages.

The Project’s outcomes

At the outset we conducted a review of the literature. This confirmed what we had expected: there was little published material to guide the work of practitioners supporting children with both visual impairment and autism. It was decided, therefore, that the major outcome should be something that would provide such guidance. The result was the guidance for practitioners, which is described below.

In addition, a major two day conference was arranged. Its title was: *Children who have VI and autism: Furthering understanding of research and practice*. The conference aims were:

- to present some of the most recent research into visual impairment and autism
- to help raise awareness of issues surrounding visual impairment and autism
- to provide information and ideas to enhance practice.

The conference took place in London in November 2010. It was a considerable success, attracting nearly 200 delegates on each day. They came from a wide range of European countries. The evaluations provided by the delegates were extremely positive.
Developing the guidance for practitioners


The guidance for practitioners is based a survey by the project team of the approaches and strategies used with children who have visual impairment and autism. We visited 17 educational settings and observed over 20 children and young people. We met key practitioners and discussed how they were meeting the needs of the children we observed.

It was very important to cover as wide a range of children as possible, so we visited children in a variety of settings, including:

- specialist schools for children who have visual impairment (which are mostly non-maintained and residential)
- a specialist school for children who have autism
- local authority day special schools
- local authority mainstream schools
- a local college of further education.

The involvement of the settings and the practitioners was crucial to the project's work. Without them, the project would not have been possible. Throughout the project, we made it clear that we would not name any of the settings involved. This was to ensure confidentiality. As visual impairment and autism is low incidence, to name a setting would, in some cases, automatically have resulted in a child being identified.

The observations of children, and discussions with practitioners enabled us to identify numerous approaches and strategies being used with individual children. In some cases, it was possible to obtain a feel for the way these approaches and strategies were helping to promote the educational development of the child in question.

A great deal of information was obtained during the survey. This was then analysed and used in writing the material contained in the guidance for practitioners.
A description of the guidance for practitioners

The material is interactive, allowing users to navigate easily between sections. It includes:

- a series of detailed case studies
- a glossary of terms
- suggested strategies for use with children and young people who have both VI and autism
- resources, with information about equipment, website addresses and a list of references
- a set of pdf versions of the materials, enabling users to print the content.

Strategies are grouped into seven areas:

- Underlying principles, dealing with the overall ethos and approach
- Promoting learning
- Managing the environment
- Promoting effective communication
- Supporting the child’s sensory needs
- Promoting wellbeing
- Promoting independence.

As music is extremely important to a large proportion of children and young people who have both visual impairment and autism, there is also a section on supporting musical skills and using musical interests.

The guidance is designed to support practitioners who are working with children who have both visual impairment and autism. It will assist teachers, teaching assistants, psychologists, speech and language therapists, physiotherapists, occupational therapists and music therapists, mobility officers and others. In residential schools and colleges it will also be of value to care staff.

When children who have visual impairment and autism become adults, their needs clearly continue. Although the guidance was designed for practitioners working with children, we believe it is also of value to those supporting adults who have visual impairment and autism. We have received feedback which provides some support for this belief.
The project focused on the approaches and strategies employed in schools to promote the development of children who have both visual impairment and autism. However, we recognised that parents and other family members play an essential part in promoting the development of these children. Although the guidance was designed for practitioners, we believe it is also of value to families. Again, we have received feedback which provides some support for this belief.

References on visual impairment and autism
I have compiled a comprehensive reading list which is also available as a pdf on my website at http://ianpbell.com/visual-impairment-autism/.

Obtaining further information
If you have any queries about the Project, or about visual impairment and autism in general, please email me: vi-autism.medina@tiscali.co.uk.