National Sensory Impairment Partnership

BRIEFING NOTE

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WRITING REPORTS FOR NON-SPECIALIST AUDIENCES GUIDANCE FOR EYE HEALTH PROFESSIONALS

Introduction

This guidance comes from the NatSIP working group led by Julie Jennings (RNIB) and colleagues with experience in Vision Impairment and has been contributed to by the Vision 2020 UK CYP low vision group. It is for eye health professionals who work with children and young people with vision impairment from birth to 25 years. Its purpose is support you, as an eye health professional so that your reports give other people or agencies a full and thorough understanding of the needs of a child with vision impairment. (Such people may include qualified teachers of learners with vision impairment (QTVI), registered qualified habilitation specialists (RQHS) and others). Your advice to non-eye health specialists will contribute to children and young people receiving the support they require.

This support may include a range of services to enable children and young people with vision impairment to make best use of their vision or other senses to enhance their life chances and achieve their maximum potential. It may also include support for parents and carers, for example signposting to benefits, emotional support, family groups, and local and national organisations for children and young people and their families.

An assessment of a child's visual function should be based on learning, social and independence needs. It can be undertaken by a number of professionals, such as an ophthalmologist, an optometrist, an orthoptist, a QTVI or RQHS, in a multi-disciplinary approach centred on the child. When a child or young person has no vision, an assessment of options for other strategies to support the child's learning, social and independence needs should also be carried out. The information provided contributes to a full and accurate assessment of need.

If the visual function assessment is not multi-disciplinary, it should link into broader habilitation and specialist education support services for the child or young person and their family. It is not just a clinical process, but is best achieved by professionals from health, education, social care and the voluntary sector working together with children, young people and their families.

Eye health professionals can contribute to this process by providing reports to other agencies for a range of purposes including:

- Education, Health and Care plans – to enable a full assessment of the child or young person's needs and support to meet those needs
- Welfare benefits claims e.g. Disability Living Allowance (DLA), Personal Independence Payment (PIP).

(See the appendix for further information).

What your report may include

For those children with some residual vision, vision assessments are usually undertaken in optimal conditions with enhanced lighting and targets with clear contrast, in order to measure the best-case functional scenario for the child. When low vision aids are prescribed, an improvement in test results is expected. Whilst it is important to recognise that low vision devices (when comprehensively introduced with appropriate training) can ensure that the child achieves better clinical scores, **reports do not always identify the functional difficulties that remain, or the implications for the child in their day-to-day environment where the visual environment may be far from optimal**. It is therefore helpful if your report can support comments from a QTVI or RQHS on the functional difficulties that a child with low vision may face in day-to-day living and learning environments.

Clinical vision reports can be full of technical terms that the reader may perceive as jargon and find difficult to understand. As a result, the potential impact of your report can be lost. Providing tailored, accessible information can help other professionals and the family to:

- understand the child's vision requirements better
- identify outcomes for the child
- improve the planning and provision of support.

By making your report accessible to non-eye health specialist audiences, you can help support decisions about a child's requirements in an educational setting, leading to improved outcomes for the child.

1. Diagnosis – Age at diagnosis and cause (if known)

This information is useful as the needs of a child who is born with a vision impairment will be different from the needs of children who lose their vision later in life. These latter may have visual memories which will be useful for understanding the world around them, but may need emotional support to come to terms with a loss of vision, particularly if it is sudden.

It will also be helpful to provide details of developmental needs such as information about the child's developmental milestones, whether the child needs more attention and supervision than a typical child and whether extra time and effort are needed to help them to learn and develop.

2. History – Current status of vision and prognosis

This information is useful to understand whether the child's visual condition is stable, or whether it is deteriorating and may cause a change in the child's reading and writing medium, for example the need to move from print to Braille or audio. This will impact on the child's ability to keep up with learning requirements during transfer from one medium to another, and may also have implications for emotional support, depending on the age of the child.

3. Visual function in daily life/corrected vision levels (visual acuity, visual field function, contrast, stereopsis and other markers of visual function)

The actual assessment used is not critical, but it is important that the results and information are reported uniformly so that comparisons can be made over time. This information helps professionals supporting the child in educational settings to understand whether a child is able to access the range of teaching and learning strategies provided in a visual way. The report reader may not be familiar with clinical terms used, so it is helpful to interpret the results clearly. For example, are there any things that the child is unable to see near to or at a distance or above and below?

Visual function is reported as visual acuity scores, both near to and at a distance, and peripheral vision, in distraction-free conditions with optimal targets. It is helpful if this is translated into functional levels which would be more appropriate for the learning environment

For example: *Sarah scored 0.5 LogMAR in the clinic which is equivalent to approximately 6/18 Snellen, but this would be best represented as 0.6 LogMAR or 6/24 Snellen in her primary classroom. This would mean that Sarah would need to be seated 4 times closer to the interactive whiteboard or objects in the distance would need to be 4 times as big for Sarah to see them clearly.*

Recommendations for a child with restriction in their visual field (breadth of vision including peripheral vision) might include interventions that encourage compensatory eye movements.

For example: *Salma has reduced peripheral vision (side vision) on both sides. This means that she needs to be placed in a central position in the classroom and those working with her should be aware that she will not see them approaching her from the side until they are directly in front of her.*

This type and level of detail of information is valuable to professionals supporting the child in educational settings so that they can understand how to adapt the visual environment, and any potential additional support needs. A typical classroom has varying levels of natural and ambient lighting, and learning materials presented in fonts and sizes that are not accessible for many learners with low vision.

4. Details of up to date prescription/provision of appropriate optical/non-optical aids, advice on lighting conditions, contrast and optimum print size, filters, tactile aids, electronic aids and other non-optical aids.

The following should be offered, as appropriate, to the child or young person, following assessment

- Prescription/provision of appropriate optical/non optical aids
- Advice on lighting, contrast and size, filters, tactile aids, electronic aids and other non-optical aids
- Training and/or therapy to enable optical and non-optical aids and other techniques to be used effectively
- Advice on alternative approaches to learning through tactile or auditory means.

It is helpful if health specialists can provide details of each child's needs, including whether, in their everyday environment, the child uses a low vision aid or other equipment, or needs help to use and maintain a low vision aid or other equipment, what low vision devices and assistive technology have been introduced and when, whether it is used consistently, and what impact it has had. It may also be helpful to state the most appropriate seating position, wider ergonomic considerations, any lighting conditions required, and details of optimum print size and contrast.

5. Training and/or therapy to enable optical and non-optical aids and other techniques/strategies to be used effectively

It is useful to understand whether the child has received training in using the aids and is independent in using them, and whether they reliably report difficulties with them, or whether they require help. This will determine whether extra time needs to be dedicated to training in the effective use of low vision aids. It is also important that professionals such as teachers and teaching assistants are trained in the appropriate use of the aid, so that they can support the child effectively.

6. Most appropriate seating position/wider ergonomic considerations e.g. reason for an abnormal head posture (AHP) with nystagmus

This information is useful particularly for children with multiple needs who may be supported by a range of professionals, such as a QTVI, physiotherapist and occupational therapist. For example, in supporting use of strategies such as eccentric viewing for children with nystagmus, a physiotherapist may be keen to keep a child's posture in midline while a QTVI may be focussed on the most effective use of vision. Shared objectives based on an understanding of the reason for an AHP will support better outcomes for the child.

7. Surgical and therapeutic interventions

It is important to know if surgery could result in improvements for the child, for example cataract surgery, retinal detachment, squint surgery etc. It is often useful to have an explanation of therapeutic interventions, such as when prism lenses are prescribed following surgery, or the impact of prescribed drugs on vision in cases such as uveitis, the implications for physical activity following retinal tear repairs, and so on. It is important for education professionals to be able to support e.g. spectacle or contact lens wear and amblyopia treatment, or the use of eye drops for conditions such as glaucoma.

8. Variability and flux (light dependent, time dependent)

It is helpful to have information on conditions that may vary with external factors, for example having reduced visual function in dim lighting or at night, or having difficulties moving from bright light to dim lightFor example, a child moving from a shaded classroom area to a sunlit outdoor space may need time to stop and adjust to the different lighting levels.

9. Vision and mobility (e.g. ability to get to places independently)

It is useful to know whether a child has problems with seeing clearly at a distance. They may for example frequently need to have things explained that they have missed visually, or they may not able to get to places independently. There may also be issues with peripheral vision, such as a lower visual field loss, which mean that they do not see obstacles such as obstructions on a pavement. It is helpful to know whether there are any problems with depth perception which might, for example, make a child less confident going downstairs. Older children with such problems may require additional close supervision when crossing roads or playing outdoors to avoid danger to themselves or others.

10. Risk factors – issues identified in relation to eye care, emotional support, social care

It is helpful if eye clinic professionals can provide information based on their knowledge of the specific child. For example, details of anything a typical child would be expected to be able to do that the child with vision impairment is not achieving yet, such as, Do they reach out to objects? Are they beginning to explore their environment? Does a child need more time or effort spent on attention and supervision than a typical child of the same age? This might be practical support such as using low vision aids. Babies and young children with vision impairment will need additional adult support to describe events happening around them that they cannot see clearly. Does the child require extra time and effort spent on helping them to learn and communicate? Babies and children with vision impairment will have regular appointments with doctors, optometrists and habilitation teams (such as mobility workers and QTVIs). Families will spend additional time at home building learning and development into their daily routines with their child. These all require extra time and effort that would not be expected of a family with a typically developing child.

Appendix

Writing reports to support a child's education

To ensure that children and young people with vision impairment reach their full educational potential, it is important that early years settings, schools and colleges have a full understanding of the child's needs, and in particular their requirements in the learning environment. This includes support given to the parents in the home setting when a baby is first diagnosed.

Information about a child's vision will, alongside information provided by other professionals, help to ensure that the child's potential is maximised and outcomes are improved by making certain that:

- plans for education, health and care support are based on a full and thorough assessment and understanding of the child's or young person's needs and the implications for learning
- any barriers to their development and achievement are identified and strategies are put in place to address them.

If a child is not making expected levels of progress, all aspects of that child's education plan must be considered in detail. A specialist may be asked to provide advice on:

- any changes to the learner's level of vision
- the effectiveness of equipment or strategies used.

The assessment will need to be reviewed regularly throughout childhood, probably at least annually. Particular attention will need to be given to transition stages, and care must be taken to ensure appropriate support is in place for transition from one educational provision to another.

Information for an Education, Health and Care needs assessment

0 to 25 SEND Code of Practice: guide for health professionals (2014)[1] by the Department for Education and the Department of Health states:

> *"Health professionals will need to contribute to section G of the plan: Any health provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN. Information should be included as follows:*
>
> - *Health provision should be detailed and specific and should normally be quantified, for example, in terms of the type of support and who will provide it*
> - *It should be clear how the provision will support the outcomes, including the health needs to be met and the outcomes to be achieved through provision secured through a personal (health) budget*
> - *Clarity as to how advice and information gathered has informed the provision specified*
> - *Health care provision reasonably required may include universal services, specialist support and therapies, a range of nursing support, specialist equipment, wheelchairs and continence supplies. It could include highly specialist services needed by only a small number of children which are commissioned centrally by NHS England (for example therapeutic provision for young offenders in the secure estate)*
> - *The local authority and CCG may choose to specify other health provision reasonably required by the child or young person, which is not linked to their learning difficulties or disabilities, but which should sensibly be co-ordinated with other services in the plan." (page 20)*

Writing reports to support welfare benefit claims

Disability Living Allowance (DLA)

DLA is a non-means-tested payment that is provided to help with the extra costs caused by the child's disability.

DLA is paid at different rates depending on how much additional help the child needs over and above the usual care needs of a child the same age. Most children with a vision impairment are eligible for the care component of DLA

[1] https://www.gov.uk/government/publications/send-guide-for-health-professionals

and some (over the age of three years) are eligible for the mobility component if they have significant additional mobility or supervision needs out of doors.

The application process for DLA is lengthy, and many families are turned down the first time they apply. The DLA application form focuses on what a child cannot do rather than what they can do. This is demoralising for both parents and professionals who are usually focusing on the positives - the child's progress and achievements.

Most eye clinic professionals already write reports for parents, or copy them into letters written about their child. When parents make a claim for DLA they do not have to provide a separate report from an eye specialist, but they are asked to submit one (along with other evidence) if they have a report to support their claim. Parents are also asked to complete the claim form with detailed medical information, so it is helpful for them if they have a report that clearly explains the implications of the optical and medical terminology used.

Personal Independence Payment (PIP)

PIP is a new benefit which is replacing the DLA for people aged 16 or over. There has been a staged roll-out of PIP since April 2013. Parents and young people can find out when PIP will be introduced in their area by visiting www.gov.uk/pip-checker/

One of the main differences between PIP and DLA is that when a young person reaches 16, *they* will be the claimant, rather than their parents. PIP is provided to help with the extra costs caused by the young person's disability; for example, if they have difficulties with daily living or with getting around, they can claim. PIP is not affected by any other money the young person may have.

Like DLA, the application process for PIP is lengthy, and many young people are turned down the first time they apply. Again, the form focuses on what the young person cannot do rather than what they can do. As with DLA, this can be demoralising.

When young people make a claim for PIP, they do not have to provide a separate report from an eye specialist, but they are asked to submit one (along with other evidence) if they have it, to support their claim. Young people are also asked to complete the claim form with detailed medical information so it is helpful for them if they have a report that clearly explains the implications of the optical and medical terminology used.

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