CVI Passport

Introduction

The CVI passport consists of three parts:

A. A manual for the practitioner. This describes how the CVI passport can be created, in consultation with parents and others who are directly involved.
B. A form to be completed by parents and/or the adolescent, in consultation with the practitioner.
C. A key card: an A5-size card that identifies the principal impediments that the child faces in everyday life as a result of cerebral visual impairment (CVI), plus the possibilities of adjustment or compensation.

A. Manual for the practitioner

Starting out

This manual describes how the practitioner can go about preparing a CVI passport, in consultation with the parents (or with the adolescent if CVI has been diagnosed at a later age). The CVI passport serves various purposes. First, it is a document that offers psychoeducational tools in relation to CVI in the general sense. It does so by explaining what good vision is and what impediments can arise in different functional areas pertaining to vision. Second, it helps persons who are directly involved with the child to recognise the CVI characteristics that it has. That is done by working with concrete examples, preferably provided by the parents or the child itself. And third, this document ensures that parents or the child can explain to people in their immediate surroundings what limitations and difficulties they experience as a result of CVI and how these might be compensated through adjustments in the approach or in their surroundings or through the use of specific devices.

The CVI passport is first and foremost a working document, of which the child and the parents are the owners.

We recommend that the CVI passport be first completed following the diagnostic phase, by the behavioural specialist who has carried out the diagnosis, together with the parents or the adolescent. Parents have just heard that their child has CVI and will often want explanation. For each individual child or adolescent with CVI it is decided who this document can best be completed with. In principle we recommend that the CVI passport be completed together with the parents when the child is less than 10 years old, after which the parents provide a brief explanation to their child. Between the age of 10 and 14 it can be completed by the parents together with their child. From the age of 14, it is best to have the adolescent personally complete the passport, in cooperation with the specialist, and then inform his or her parents. The form of feedback and who is present then will be decided at the end of the process with the parents or their adolescent.

Since CVI has become an umbrella concept that encompasses various visual functions that may or may not be affected (or to a greater or lesser extent), this passport provides excellent reference points for psychoeducation. Parents, or the child or adolescent, are unlikely at this point to come up with many examples of their own. We therefore recommend sitting down together again with the parents and the child/adolescent at least four months to a year later (certainly in a treatment programme that involves compensation or visual training) to discuss the various steps and characteristics. If the treatment is shorter, then this meeting can be planned at the end of the treatment. This makes for a more concrete picture for the parents and provides room, for example, to incorporate growth resulting from a training programme in the document itself. Also it is not always evident at the start what compensation skills the child itself is able to deploy or learn, but these can be added at a later point in time. We recommend agreeing in a multidisciplinary setting who is going to do this. Our advice is to have this done by the field educational supervisor or the practitioner involved (the development supervisor or therapist).

While diagnostic practice often looks at visual ability at the functional level, this CVI passport will translate this to activity and participation level. It describes various skills and whether the child possesses these or not, so that the parents get insight into what CVI means for their child in everyday life. The CVI passport starts with a global definition of visual information processing

problems. That is followed by a brief description of the various visual functions. This manual contains concrete examples that can be discussed with the parents. In practically all cases the problems in the processing of visual information will not involve all visual functional areas. The functional areas that are not affected will be removed from the CVI passport by the behavioural specialist after a brief discussion, so that the ultimate document contains only those functions that are relevant for the child. It will also identify precisely those examples that are most recognisable for parents or the direct surroundings.

Completing the CVI Passport

The CVI passport starts with a general description of what CVI – cerebral visual impairment – entails. It is important to explain to parents and others involved that CVI is an ICF-based description and that what is important is the impact that the functional impairments have on the everyday life of the child. Where known, a link can be established with the brain damage of a child.

Next, the various functional areas are identified, in line with the diagnosis protocol. The intention is to discuss these with the parents one by one, to explain what good vision means, and to identify to what extent their child deviates from this. We presume here that it is useful to know what good vision involves, so that the visual limitation can then be understood better. A distinction can then be made between impairment level and the experience of problems or minor impediments within a specific category. This must ultimately lead to a picture of the consequences of the visual impairments for the everyday life of the child.

A description is given below of the various functional areas from the CVI passport, along with a brief explanation in simple terms that is suitable to discuss with parents. In addition, a list of examples is presented of recognisable impediments that a child may experience within a specific functional area in everyday life. The list of examples is obviously not complete. It can, however, serve as a starting point for a discussion with parents, with parents and child, or with the adolescent. Where available, exercises are presented that parents can perform, for them to get an idea of what effects a specific visual impairment can have on a person's ability to perceive things. Following the explanation and presentation of general examples, a discussion with the parents takes place to see to what extent their child experiences problems in a specific regard. The purpose of all this is that the parents can themselves explain what they consider important within the functional area and that this is included in the passport. In that way you will know what the parents have picked up of the information, how they themselves interpret the problem (make sure you link up with this as closely as possible!), and what additional information is required. We assume here that the practitioner decides what must be minimally described (since it is relevant for the child) and that the parents decide *how* this is expressed.

As stated earlier, some visual functions will be removed from the passport following the meeting since they are not relevant for the child in question. Some visual functions, however, may be included under the compensating factors if the child uses these (for example the application of visual memory for visual closure tasks). The CVI passport thus strictly contains the key information that optimally describes the visual functioning of the child in question.

General description of CVI and the visual hierarchy

The general objectives for completing the CVI passport are discussed with the parents. This discussion includes a general explanation of CVI. It is important to explain that visual perception involves both the eyes and the brain. The brain *processes* what the eyes provide as input. To be able to see well we need good eyes. If the quality of the input from our eyes is low, the processing of that input will be that much more difficult. The following metaphor can illustrate this. Our eyes function like a camera that records the surroundings. The processing of the images produced by the camera is done by a computer with all sorts of software (the brain).

Conditions for proper perception

During the introduction we also look right away at the conditions that are necessary to be able to perceive. We consider it important to discuss these right from the start, so that parents are aware of the hierarchical functioning within perception. The nature and severity of problems and limitations that a child with CVI experiences depend on the nature and severity of the child's current impairment(s), but also on its other characteristics and abilities. After all, how good a child sees depends not only on visual functions. Both the low and the high visual functions depend on a functional hierarchy, where a child's emotions, needs and motivations and its direct surroundings are at the top. If a child does not want to look properly, or if it does not look in a focused way due to distractions in its surroundings, then it will not use its visual functions to the full.

First, the emotions, motivations and needs of the child, along with the characteristics of its surroundings, determine the use of attention management and other executive functions. Without sufficient attention to the visual sense, adequate perception will not come about. Because of this importance of attention, extra explanation is included in this manual. The general conditions for looking are not covered until at the end of the CVI passport, among the other relevant factors. After all, within the CVI passport we want to focus first on the visual functions, without ignoring the impact of other problems.

Attention

Before any perception is possible, the ability to see must be considered. Only with attention for the sensory ability to see will the information that the eyes present us be processed further and will the high visual functions be engaged. In children with CVI, looking is sometimes not primarily a sensory ability to observe the world around them and to adjust their behaviour accordingly. Together with the parents, the viewing behaviour of their son or daughter must also be examined. Does the child's focus lie on visual perception? Does it have a relatively high level of attention for the other senses? Is the child visually curious? Can it focus on visual elements only briefly? Does the child not respond to strong visual stimuli, or at least not always? Does its looking behaviour vary; in other words, does it succeed in looking one moment but not the next? The level of attention for this looking behaviour is described under other relevant factors.

Low visual functions

Visual sensory functions

These are the functions of the eye itself, such as the ability to see sharp, to signal information over 180 degrees (peripheral vision), to observe colours and contrasts, and to estimate depth and distance. To be able to explain to parents to what extent the low visual functions of their child are impaired, it is necessary to relate this to what seeing "well" implies. For that reason, we first explain what proper eyesight entails. After this we examine the potential limitations within the various functions.

- *Visual acuity*
  Being able to see well is referred to in optical terms as visual acuity of 1.0, also commonly called 100%. Children with poor eyesight have visual acuity of 0.3 or lower. Acuity between 0.3 and 0.5 we call slightly lowered, while between 0.5 and 1.0 is referred to as subnormal. We recommend, for example, explaining what visual acuity of 0.5 means for the child's ability to observe details. Acuity of 0.5 means that details are seen at a distance of 5 metres that someone with good eyesight would see from a distance of 10 metres. In other words, an object must be so many times closer for the same result, thus twice as near in case of an acuity of 0.5. As such, the child in question, when looking at a tree, can see the trunk and the foliage, but it would have to approach the tree to roughly 5 metres to be able to see the shape of the leaves, whereas someone with good eyesight would see the same details from a distance of 10 metres. A comparable calculation can be applied for objects nearby (50 centimetres instead of 1 metre, etc.). Parents would, for example, notice a child's reduced visual acuity when they see it reducing the viewing distance for watching television, using a tablet or telephone, reading a book, playing with toys, etc.

- *Range of vision.*
  Our range of vision is the total area that we see at a single glance when focusing one eye at a specific point. A full range of vision covers 180 degrees horizontally and 130 degrees vertically. This means that, when stretching your arms to the left and right, you can notice the wiggling of your fingers. Obviously, the acuity of your sight at the outside of your range of vision is less than in the central part. A child with a limited range of vision would, for example, be unable to see part of the surrounding space or of a picture, a plate or a line of text. This might be evidenced by the child bumping against doorposts or furniture, leaving food on the side of its plate untouched, difficulty in following a line of text or in reading long words, etc. It is wise to specify to parents which part of the range of vision is missing (left, right, central, upper, lower). To illustrate this, a picture might be used that shows, by covering this with a black strip, which part their child cannot observe. Alternatively, you might use clock hours to express the loss of vision.

- *Colour recognition*
  This is the ability to distinguish colours. If the child finds it difficult to recognise colours, this is indicated as such.

- *Sensitivity to contrasts*
  Sensitivity to contrasts refers to the difference in clarity between object and background. If a child has a reduced sensitivity to contrasts, it may find it difficult to see a white cup on a white table. A blue cup on the same white table will be easier to see. Reduced sensitivity to contrasts may also impact the ability to recognise facial expressions and transitions that involve little contrast, such as on roads and sidewalks.

- *Ability to perceive depth*
  Binocular (or stereoscopic) depth perception is the ability to focus with two eyes at the same point and to let the two images melt into a whole, i.e. into a three-dimensional image. The brain compares the separate images of the two eyes and combines these into a full image, thereby enabling us to judge the distance to the object that we see. For a person with only one good eye or who is cross-eyed it is thus more difficult to judge distance. Still, it is also possible to see depth with only one eye (monocular depth perception). An object that is distant is generally seen less sharp. Also, a tree that is far away appears smaller than a similar tree that is nearby. And when we move, we see the objects around us shift in relation to each other. The experience that our brain has with seeing objects in perspective, plus the presence of shadows, also helps us in getting spatial perception. In ordinary day-to-day activities, a person who looks with just one eye will generally not experience much problem with this. You do notice, however, that for such a person it is more difficult to walk across a beam. Certain professions and sports such as tennis require good depth perception. Participating in a sport like this will be more difficult for this person than for someone who has optimal depth perception.

- *Accommodation*
  Accommodation is sharpening our view of what we see, whether near or distant. A child with an accommodation disorder can experience reading problems, hazy or double vision, fatigue and/or headache (often above the eyes near the eyebrows or in the forehead).

Oculomotor functions

These functions relate to the ability to move the eyes.

- *Eye movements*
  Each eye has six external muscles. These ensure that the eye can move in every possible direction. Each eye muscle has its own function. The eye muscles are directed by the brain. When an optic nerve gives less information to one of the eye muscles or none at all, this affects the ability of the eye to move and the position of the eye. The ability to move and the eye position can also be disturbed by muscle diseases or a mechanical restriction to one of the eye muscles.

- *Convergence*

When we view an object from a short distance, both eyes focus towards the nose to see strictly this object. This movement is called convergence. The ability to converge is important for activities at short distance such as reading, writing and work at a computer.

- *Saccade*
  A saccade is a quick, simultaneous movement of both eyes, intended to find a new fixation point. Saccades are used, for example, while reading, to move from one word to the next.

High visual functions

Visual selective attention

A visual image usually contains too much information to take in all at once. We therefore need to select within the total range of vision. The first selection involves the object on which we want to focus our eyes. The eyes are always directed at a single point. When we focus both eyes at one point, we see more than that single point. We use our function of visual selective attention to select a part of the visual field, usually an area around the point that our eyes focus on. We determine the size of this area partly on the basis of our personal needs and motivation, partly on the basis of the intensity of the visual stimulus. For example, when we focus our eyes on the door latch of a car, we see either only the latch or the entire car. We usually first select a large area in order to get an overview and the correlation between visual elements. This is called **global visual selective attention**. Following this, we zoom in on a small area in order to view a detail. That we refer to as **local visual selective attention.** Within the visual field we can also select on the basis of other visual properties, such as a specific form or colour.

Some children with CVI always have a large selected visual attention area. Their ability to zoom in is disrupted. Others are always zoomed in. They permanently select a small visual attention area, and thus do not have an overview. Still other children with CVI needs lots of time to switch from a large visual attention area to a small one or vice versa. Aside from all this, some children have a rigid visual attention window that cannot zoom in or out.

Children who find it difficult to make their visual attention area smaller (a disorder in their local visual selective attention) may experience problems with:

- Looking for a toy in a crate, clothing in a wardrobe, finding their coat on a hall stand.
- Recognising figures or objects that partly overlap each other.
- Observing in visually crowded situations, such as a birthday party, an interior playground, etc. Such children then often either become very boisterous, or they withdraw from the rest.
- Looking up a detail in an illustration, such as in a picture book.
- Finding their parents (or another familiar person) in a crowded situation, such as in the playground or supermarket.
- In the social area, this can lead to problems in the ability to adequately recognise emotions or even faces.

Children with problems in this area are often inclined to significantly shorten their viewing distance when working with crowded work sheets or when watching television. In that way they make their visual attention area smaller in a natural way (the closer, the more information on the sides falls

automatically away), and details are at the same time projected larger on the retina. This can also be regarded as an appropriate compensation strategy.

Examples of situations that children may find difficult when they have a visual selective attention field disorder (global visual selective attention):

- Difficulty overseeing traffic situations; too much time is needed to oversee the situation.
- Focus is strictly on visual details rather than on the whole.
- Difficulty interpreting pictures that are incomplete or lack details.
- Difficulty with overview and thus understanding of visual scenes and/or larger pictures.
- Difficulty overseeing quantities all at once.
- Difficulty orienting on a page.
- Difficulty in looking up and down from textbook to exercise book and vice versa.
- In the social area, difficulty in seeing links between what happens in the schoolyard or during physical education.

Parents can personally experience these problems by, for example, putting on cylinder glasses and then making a perception task for visual closure or having to describe a larger picture.

Visual identification

Visual identification involves the ability to adequately recognise pictures, photos, objects or symbols.

Examples of situations where children encounter problems when their visual identification ability is impaired:

- Difficulty learning geometric shapes (triangle, square, circle, oval, etc.)
- Difficulty mastering letters and word images
- Recognising persons in daily life, also photos
- Recognising emotions and facial expressions of persons in daily life; also photos
- Difficulty understanding and/or identifying three-dimensional objects, photos of objects, detailed coloured drawings or pictures, line drawings (black and white), emotions on faces (some or all), colours and forms (some or all)
- Difficulty recognising or identifying objects, pictures, letters, figures, faces.

Parents can experience the difficulty of recognising a face by printing photos of familiar persons. When removing a person's hair and showing the photo upside down, the face becomes difficult to recognise. Turn it around and you immediately see who the person is.

Keep in mind that this visual function is seldom affected in children and adolescents. A lack of visual identification is rather the result of a disorder in the global visual selective attention, as a result of which "the picture" (the word image or the figure) cannot be stored in the visual memory. From a distance, the identification can become more difficult as a result of a disorder in the local visual selection attention (recognising mother's face in the schoolyard among the other parents).

Visual-spatial functions

Visual-spatial functions involve in the first place the observation of the orientation of objects, for example whether the handle of a cup is on the left or right side. Recognition of the direction in which an object is turned also falls in this category. Adequate distinction is made between left and right, above and below, front and back. This way, children are able to learn routes in an area, a

building or outside on the street. Spatial positions are linked to a sort of internal map, making it possible to remember the relations of objects with respect to each other.

Second, when their visual spatial observation ability is intact, children are able to position elements correctly in relation to each other, for example when building with blocks. Pictures (two-dimensional information) can be converted to objects (three-dimensional information) and vice versa. We call this location perception.

Third, the ability to observe movements falls under visual-spatial functions. Children can see whether something moves, in what direction it moves and how fast it moves. This is important, for example, in traffic: is the car coming towards you, or is it instead moving away?

Examples of situations that children may find difficult when their visual spatial functions are impaired:

- Difficulty with spatial orientation
- Difficulty finding the beginning of a line on the page
- Difficulty following a familiar route on your own, even short distances
- Difficulty finding your way
- Difficulty judging whether an object is moving
- Difficulty judging the speed of a moving object, e.g. how fast a ball is coming at you.
- Difficulty recognising or identifying objects from a moving vehicle
- Difficulty recognising or identifying moving objects
- Difficulty determining where an object is in relation to another object, or how two objects are oriented towards each other.
- Difficulty mastering letters and/or numbers (in particular mirrored signs, such as the letters ‘b’, ‘d’, ‘p’ and ‘q’)
- Difficulty with the concept of visual-spatial figures (copying a drawing or imitating an object)
- Difficulty assessing the direction of lines
- Difficulty telling time (on an analogous clock).
- Difficulty with spatial relationships.
- Difficulty with the concept of mirror images.

Visual-motor functions

When the visual-motor functions of a child are properly developed, a child is able to move quickly and in a focused way. The child then converts the visual information of the world surrounding it at great speed, without having to think, into very specific action. The child can control its hands and feet adequately simply by looking (eye-hand and eye-foot coordination).

Examples of situations that children may find difficult when their visual-motor functions are impaired:

- Grabs or reaches next to an object
- Frequent little accidents when picking up food or drink
- Slow in targeted movements
- Difficulty catching a ball
- Difficulty aiming a ball
- Difficulty hitting a ball with the foot and/or kicking it in the right direction

- Difficulty drawing the right direction of lines
- Difficulty writing neatly (lines and letters are warped and wiggled)
- Frequently bumps into others or objects
- Looks away in targeted actions

Parents can themselves experience problems in the visual steering of motor functions. For problems in eye-foot coordination they can walk down a stairway while looking through reverse binoculars. To experience problems in eye-hand coordination they can be asked to draw a straight line in a printed star while only being allowed to look in a mirror placed above.

Visual storage memory

Where and what was it? The storage location of visual information. The ability to form (or deform) a visual image ("image database").

Our visual storage memory enables us to form and deform mental visual images. In other words, it enables us to see things that are not physically present at that same moment. For example, using your visual storage memory you can imagine the face of your mother, or the colour red, or you can mentally turn the pieces of a puzzle. Our visual storage memory, the (de)formation of visual images requires lots of focus: this ensures that your visual image is made consciously, it enables active deformation (such as mental rotation). The liveliness of mental visual images, as well as the ease with which a visual image can be deformed, differs greatly from one person to the next.

Examples of situations that children may find difficult when their visual memory is impaired:

- Much repetition needed to remember visual information
- Difficulty with free drawing
- Difficulty with shaping objects mentally (without a visual example) and thus drawing (of geometric forms and other visual-spatial figures)
- Difficulty with mental turning (of figures)

Parents can experience this by asking them to think of a 'pink elephant'. Most people have never seen a pink elephant but are nonetheless able to conceive one in their mind. Parents can also be asked to draw a familiar symbol by heart, such as the emblem of the Dutch Railways. Even though this seems like a simple exercise, for many people it is still difficult to do this accurately.

Pace of visual information processing

This is the speed with which a person responds to visual information. An impediment or disorder in this function means that more viewing time is needed to process visual information. Some children and adolescents do not have any of the functional disorders described earlier, but visual information may still penetrate to them slower compared to other people even though they cannot be called "generally slow". That may be because they are able to process auditory information quickly enough and/or because they are just as quick as anyone else in accessing information that is stored in their brain.

Examples of situations that children may find difficult when their pace of visual information processing is impaired:

- Difficulty reading subtitles
- Difficulty following quickly changing situations (e.g. in traffic, physical education, films)

Other relevant functional areas

- Executive functioning
- Attention (discussed above)
- Intelligence level
- Behavioural factors
- Motor system
- Sensory information processing

Children may also find it difficult to process various sensory stimuli simultaneously.

- Looking away during intense listening
- No eye contact during conversation
- Steering an action visually, but looking away from the place of action when an object is placed

B. The CVI Passport

<table>
<tr><td colspan="2">CVI Passport
Name
Age</td></tr>
<tr><td colspan="2">CVI is a collective name for visual impairments that result from damage to or abnormal development of the brain. The impairments and limitations falling under this category relate to the processing of visual information by the brain. Perception involves both the eyes and the brain. The list below contains a description of the various visual functions that are impaired in [name]. First, we state the specific functions of the eye. Following that, we list the functions that are involved with the processing of the visual information in the brain.</td></tr>
<tr><td colspan="2">Low visual functions
The low visual functions directly relate to the eye (compare this to a camera).</td></tr>
<tr><td>Visual sensory functions
These are the functions of the eye itself, such as the ability to see sharply, to signal information by means of peripheral vision, to observe colours and contrasts, and to estimate depth and distance.</td><td>• Visual acuity
• Range of vision
• Colour perception
• Contrast sensitivity
• Depth perception
• Accommodation</td></tr>
<tr><td>Oculomotor functions
These functions determine the ability to focus the eyes properly.</td><td>• Eye movements
• Convergence
• Saccades</td></tr>
<tr><td colspan="2">High visual functions
The high visual functions relate to the processing of visual information from the eyes in the brain (compare this to a computer that adapts and processes images).</td></tr>
<tr><td>Visual selective attention
This determines which visual information from the field of vision (the eyes) we focus on. The direction and dividing of attention to visual information in the field of vision.</td><td>• Global visual selective attention
• Local visual selective attention
• Selection on a specific property</td></tr>
<tr><td>Visual identification
The ability to recognise pictures, photos, objects, symbols, etc.</td><td></td></tr>
<tr><td>Visual-spatial functions
The ability to recognise directions, to place elements in relation to each other, and to</td><td>• Location perception
• Orientation perception
• Movement perception (movement, direction, speed)</td></tr>
</table>

observe movement.	
Visual-motor functions The ability to convert visual information at high speed and without thinking into an accurate movement.	
Visual (storage) memory Where and what was it? The storage location of visual information. Ability to form (or deform) a visual image ("image database").	
Pace of visual information processing The speed at which a person is able to respond to visual information.	
Other relevant areas	• Executive functioning • Attention • Intelligence level • Behavioural factors • Motor system • Sensory information processing
What can we do about it?	
Personal compensation by [name]	• Description of personal strengths • Description of positively developed functions
Adjustments in immediate surroundings	• How can others help me to see better? • How can the surroundings or the material be adjusted so that they are visually more accessible for me?
Devices	• What can help to make my problem smaller (spectacles, computer, etc.)?

C. The key card