

Enhancement of visual abilities of multidisabled children with CVI (a scientific researchproject)" Juli 2009

Topic: Early Intervention and MDVI

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Abstract

We will present a practical example of the enhancement of the visual abilities of multidisabled children with CVI in a post-rehabilitation stage through long-term treatment. The assumption is that consistent visual stimulation and training is necessary to maintain the progress in visual abilities obtained during rehabilitation. However, this is difficult to maintain in the practical setting of special daycare centres.

During a pilotstudy in 2005, we have monitored the progress of a group of multidisabled children in a special daycare centre during 12 months, receiving weekly individual sessions from our team. The monitoring is performed with an observational instrument and a questionnaire for parents and caregivers, developed by Visio.

In 2008 Visio has started a scientific researchproject to validate the use of this intervention (from good practice to evidence based). Two researchgroups are formed (multiple baseline design). The intervention consists of visual training with severely multidisabled children, aged between 3 and 12 years who visit special daycare centres. The first group of children will have visual training between march and november 2009. The second group will receive training between january and septembre 2010. Monitoring is executed before starting and after 9,18 and 24 months. Monitoring consists of standardized observations, a questionnaire for parents and teachers, Preferential Looking Test and an objective method of measuring eyemovements (in cooperation with the Vestibular-oculomotor research group, dept. of Neuroscience, Erasmus MC, Rotterdam).

Results of the pilotstudy and first results of this new researchproject will be presented.

Sheets powerpoint presentation

2. Enhancement of visual abilities of multidisabled children with CVI (a scientific researchproject)".

Topic: Early Intervention and MDVI

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I will present a practical example of the enhancement of the visual abilities of multidisabled children with CVI in a post-rehabilitation stage through long-term treatment. The assumption is that consistent visual stimulation and training is necessary to maintain the progress in visual abilities obtained during rehabilitation. However, this is difficult to maintain in the practical setting of special daycare centres and at home by parents because of the time they need of nursing these children.

The effect of visual training mostly is practice based, it's still less evidence-based, especially for the group multi-disabled children.

4. Question for this pilotstudy

- How can we, Visio, answer the demand for longterm training of visual functions and capabilities from multi-disabled children visiting a special daycare centre?
- **Assumptions**
- Offering weekly visual training by a special needs worker will improve the visual functioning and viewing behaviour of the child
- The child experiences this individual training as a pleasant activity

The children who cooperate to this pilot study all have a period of rehabilitation by Royal Visio. During this period of assessment and rehabilitation we advise the careworkers and parents about visual stimulation and training, adapting the environment and necessary compensation strategies.

5. Purpose

- Continuation of visual stimulation and visual training
- Maintain the children's level of visual development and functioning
- Following the child's developmental steps; and create new opportunity's and visual tasks for this individual child.
- Children enjoy using their vision during the visual activities offered by the special needs worker from Visio; an important aspect so the child stay alert and active.

7. Visual stimulation, visual training

- Methodical intervention to improve the child's visual functioning
- Training adapted to the child's individual needs – *this is an important aspect due to the effectiveness of the intervention (see literature)*
- Same set-up of individual sessions for each child
- Specific instructions to special needs worker for each child about the visual development; *based on the findings during the rehabilitationperiod.*

Visual stimulation is aimed to stimulate the awareness of visual stimuli, visual training targets visual skills like fixations and smooth pursuit.

8. Study population

- 12 children who are visiting a special daycare centre for severely multi-disabled children, aged between 5 and 15 years

- Intervention after a period of rehabilitation.
- Some visual reactions during the period of rehabilitation
- Indications for CVI

A practical definition:

'If the limitations in the child's visual functioning cannot be attributed to ophthalmic problems or other dysfunctions, then we speak of CVI. The feature of looking behaviour plays an important role in CVI.

Steendam 2007 – She will explain much more in the next presentation.

During this pilotstudy, we have monitored the progress of a group of multidisabled children during 12 months, receiving weekly individual sessions from our team. The monitoring is performed with an observational instrument, visual assessment and a questionnaire for parents and caregivers, developed by Visio.

The developmental age of all children is below 12 months. All children suffer with a lot medical problems, severe locomotive limitations and most of the children have epileptic.

All these children have shown some visual reactions in the previous period of rehabilitation. So we know that visual training would be relevant.

11. Results 1 *There is an improvement of*

- Improvement in visual functioning in all children
 - Visual acuity improved, measured by Teller Acuity Cards *Thus is a preferential looking test, with lines, I show you a picture later.*
 - Distance of viewing at objects and duration of visual fixation have increased *for example from 15 to 30 cm, or from 30 cm to 1 meter.*
 - More visual reactions to more diverse materials – *I show you later a picture of materials as an example*

12. Results 2

- Improvement was seen particularly in 6th – 12th month of intervention – *this gives an evidence of the need of longterm training*
- Variability in visual functioning due to CVI is still present
- The children appear to enjoy visual activity more
- Behavioural aspects and physical discomfort clearly influence visual functioning

13. Recent research project

14. Aim of research

- Measure the effect of weekly visual training, by a special needs worker from Visio, on the viewing behaviour of (severely) multi-disabled children.

On special daycare centres, a special needs worker from Visio is going to these centres to work with the children in their own natural environment

15. Research design

- Quasi-experimental design
- Two groups, each 11 children; 6 special daycare centres
- 1st study group – visual training 03-2009 to 11-2009
- 2nd study group – visual training 01-2010 to 09-2010

- 3 moments of measurement

16. Research question

- What effects can be measured in the visual behaviour of severely multi-disabled children who receive weekly visual training on an individual basis?

17. Expected results

- Improvement in the child's visual functioning and viewing behaviour:
 - Longer fixation duration
 - Ability to follow a visual stimulus for a longer period
 - Improvement of visual following (jittered to smooth pursuit)
 - Increase of viewing distance on static or tracked objects
 - Longer visual concentration when offered several visual stimuli.
 - More visual reactions to a greater assortment of visual stimuli (*categories are lights, black and white, shiny, fluorescent, bright colours*).

18. Methods of measurement

- Systematic observations with standardized observation materials (Sonksen 1991; ZieZo 2008 Royal Visio Leiden)
 - in cooperation with Radboud university Nijmegen
- Visual Assessment (preferential looking test)
- Eyetracking method
 - - in cooperation with dept. of neurosciences Erasmus university Rotterdam; Johan Pel; j.pel@erasmusmc.nl
- Questionnaire on Visual functioning for parents and nurses/teachers.

19. Observationscales 1 Sonksen, P.M., Petrie, A, Drew K.J. (1991)

This material and the observational scale has been described in this article. The Radboud university is using this and I have had some meetings with Liesbeth van Beijsterveld.

20. Observationscales 2 Royal Visio Leiden 2008

Developed within our team, based on the normal visual development and practical experiences.

21. Visual assessment

Assesment by an orthoptist, preferential looking test, eye-movements and field of vision.

22. Eyetracking method

This method is developed by the Erasmus university. The child is shown visual stimuli and with infrared cameras the eye-movements are measured. Data gathering is done by a computer.

It's a very new and promising method. It's amazing it works for this population of severe multi-disabled children.

23 & 24 examples eyetracking method

25. First impression research group

- 11 boys, 11 girls visiting 6 different special daycare centres
- Developmental age below 12 months
- Physical age between 4½ and 12 years
- Range of vision from 0.03 to 0.5 (most 0.24/0.3)
- Indications; strong evidence for CVI
- Distance acuity for most children immeasurable
- Large variations in duration of fixation 1- 65 seconds

26 & 27. Graphics eyetracking method

You can see here the visual latency time of two children. Normally is a child going to look at a stimuli in a fraction of a second. This children need much more time. The cloud of fixations round a stimuli is normally very small, Progress is measured when the 'cloud' become smaller.

Literature

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