

Developmental setback in children with congenital blindness

Review of literature and record analysis

Poster presentation, ECPVI, Bratislava, 20.11.2014

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Ellen van de Broek and I are clinical child psychologists working with blind and partially sighted children for over 25 years.

We are concerned about a group of congenital blind children we followed over these years: it is our clinical impression, supported by assessments, that these children developed well in their first year but had a serious setback from 18 months onwards and/or developed specific behaviour; autistic like features. Some of these children recovered, most did not.

We cannot really pinpoint the risk factors and so do not know enough how to adequately help these children recover.

We received a grant that enabled us to carry out a literature review and record analysis. This work is still in progress. We would like to exchange views on our preliminary findings:

1.literature review

The developmental Vision Service in London (a.o. Cass, Dale, Salt, Sonksen) published about this "Developmental setback". It concerns retrospective research on a database of 1300 children with VI: 30% of the children with Profound Visual Impairment (no form vision) regressed after normal developmental progress.

We found no publications from other sources and no publications on prospective research.

We carried out a review of 19 longitudinal studies from 1957 and found confirmation (descriptions of regression/setback) in a considerable amount of these studies although DS had not been the focus of these studies

2. We performed a record analysis of our own caseload, this confirmed the findings of the London group: 30% DS.

Preliminary conclusions:

These are alarming findings: the period from 18 month onwards seems a vulnerable period for children with congenital blindness to develop major problems. We need/recommend:

- Scientific: prospective research on a European scale with a uniform database to pinpoint contributing/risk factors.
- Clinical: in the meantime intensive assessment and treatment of children by specialists as soon as signs of DS reveal.

We would like to invite you to our poster presentation to exchange views!

This research is part of a larger project concerning young blind children.

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Other topics are:

- *Participation of parents. Amongst others the development of a website for parents of young blind children to share information.*
- *Development of an educational programme for teachers, early interventionist, psychologists working with children aged 2 to 6 year*