

## The Management of Children with Visual Impairment

Paul Polani Lecture  
BACD annual conference 2009

Alison Salt,  
The Wolfson Neurodisability Service,  
Great Ormond Street Hospital for Children NHS Trust

## Developmental Vision Service

Multidisciplinary team  
Development and vision of  
children with VI  
0-5+ years  
Clinical leads: Alison Salt  
and Naomi Dale

The Wolfson  
Neurodisability Service,  
Great Ormond Street  
Hospital (GOSH)/  
UCL, Institute of Child  
Health  
Neuroscience Unit

## Management of the Child with visual impairment

- Parents - The impact of the diagnosis and support required
- The young child – the challenges for learning
- Disordered development
- The Developmental Journal for young children with VI – a tool to support parents and partnership working
- The ideal care pathway
- The role of the paediatrician

Parents fear there child will experience:  
darkness, emptiness  
helplessness  
isolation

Be:  
vulnerable, defenceless  
dependent on others

*Sonksen 1989*

## RNIB survey (1996) 'Taking the time' (n=21)

- **Diagnosis always traumatic**
- **Negative experience:**
  - Not listening to parent's first worries
  - Long wait for referrals for first tests
  - Lack of information in the early stages
    - where to get help
    - about the condition

## Messages from Parent focus group

The focus groups highlighted

- the immense emotional needs of parents at the time of diagnosis
- early identification and early support for parents following diagnosis is essential

## Parents of a child with a visual impairment :

### Feel less confident

- about their ability to help their baby learn new things
- about doing what they would normally do with young children /siblings

### Need support

- to know how to interact with their baby
- to assist their child to learn and reach their full potential

## Visual impairment leads to *developmental challenges* in All areas of development

Findings from practice and research

Developmental vision clinic

Great Ormond Street Hospital for Children

## Developmental Vision Team Great Ormond Street Hospital for children

### 30 years

- clinical work and research
- designing, developing and evaluating materials, tools and programmes
- to promote early development and vision for babies and young children with VI and their families

Sonksen 1983, Sonksen et al 1984, Sonksen et al 1991, Sonksen and Stiff 1991, Cass et al 1994, Dale and Sonksen 2002, Dale 2005, Salt and Sonksen in press 2006

## Vulnerable processes

- integrating senses in the first year of life
- making their world meaningful
- linking language to meaning
- becoming aware of their movement potential
- sharing attention (joint attention)
- becoming social and communicative

## Early Social Communication in children with VI

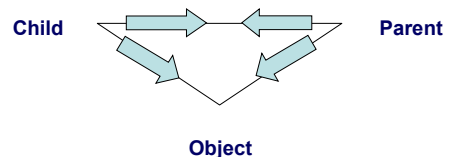
Under 18 mths

No significant differences in social communicative behaviours \*

between all visual level groups

\*Questionnaire survey (N-74) Dale et al

## Joint referential attention

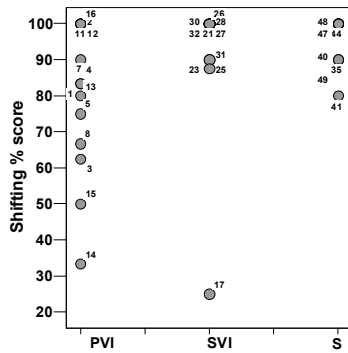


Gaze following, pointing, showing, giving

? Precursor to language development, referential communication, 'theory of mind'

## Results - Shift

Tadic, Dale and Pring 2008



$F(2,46)=5.513, p=0.007$ ; PVI < Sighted and SVI, SVI = Sighted

## Core vulnerable processes

- Difficulty with activating and integrating sensory experience in first year of life
- Attention regulation and control
- Behavioural flexibility/ shifting
- Joint attention and social communication

Most extreme in children with NO form vision (Profound visual impairment)

## Developmental Vulnerability



## Adverse outcome

Cass, McConachie and Sonksen 1994

Children with documented normal progress during the first year

Retrospective database study

Subjects: - 102

- all visual disorders
- all degrees of VI

Developmental outcome

- Reynell Zinkin Scales for VI children

## Visual level

NO Form vision

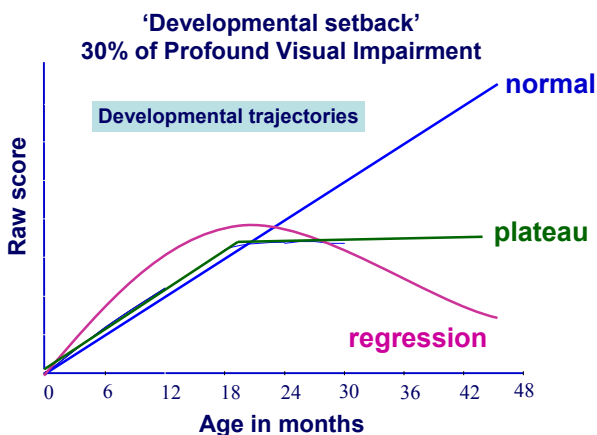
Profound VI (PVI):

No visual awareness, or awareness of light or of objects that reflect light only

Form vision

Severe VI (SVI)

awareness of a 12.5 cm coloured ball spinning at a distance of 25-30 cms, or better



## Prevalence of 'setback'

'uncomplicated' primary visual disorders

N = 69

Whole sample 15 (22%)

PVI	9 (33%)	$PVI \ v \ SVI \ p < 0.001$
PVI-SVI	5 (100%)	
SVI	1 (3%)	

Dale and Sonksen 2002

## Features of children with 'setback'

### Impairments in

- ▶ Social interaction
- ▶ Communication and language
- ▶ Play and behaviour

## Risk factors for setback

- any VI disorder
- 0 – 3 year age period
- Profound visual impairment, lack of 'form' vision (Profound visual impairment under 10-16 months)
- Boys 4:1
- ? psychosocial and familial environment
- Higher number of brain lesions – non-specific

## Is there a recovery?

No total recovery

4/11 showed partial recovery\*, but not in communication skills

\*Linked to changes in developmental environment

Cass, McConachie and Sonksen 1994

*Clinical follow up*

10 children + setback

All reached diagnostic criteria for autism (ICD-10)

DVC team 1999-2004

## Prevalence of autism in VI

- 7 out of 27 (26%) Fraiberg (1977)
- 10 out of 24 (42%) Brown et al (1997)\*
- 3 out of 18 (17%) Tadic et al (2005)\*\*

\* Childhood Autism Rating Scale (CARS), Behaviour Checklist for Disordered Preschoolers (BCDP), DSM-III-R

\*\* Autism Screening Questionnaire (ASQ) In Pring, L. (Ed) Autism and Blindness, Whurr 2005

## Questions

- Is developmental 'setback' an early manifestation of long term autistic spectrum disorder?
- What are the causal mechanisms?
- Can it be prevented or ameliorated?

## Risk periods

Infancy – activation and integration of senses

Second year of life – attention control, shared attention

## Severe / Profound Visual Impairment from birth

### is a Developmental Emergency !

- Intensive support from the earliest days of infancy
- appropriate early developmental (including vision) guidance and promotion
- specialist local support with parents and key workers working together

## Government policy context

### Early Support

*DfES funded*

*to achieve better co-ordinated family-focused services for disabled children and their families... (0-3 YEARS)*

*All children's centres are expected to use these approaches and materials,*

## Developmental Journal for Children with Visual Impairment

### Developmental Vision Team

Great Ormond Street Hospital NHS Trust,  
UCL Institute of Child Health, London

Alison Salt, Naomi Dale, Jackie Osborne and Valerie Tadic

Funded by Department for Education  
and Skills (DfES, UK)

## Developmental Journal for Children with VI

For babies and young children (0-36 months)  
with severe and profound VI

- to be held by families
- used jointly by parents and professionals
- supporting partnership working

## Developmental Journal for Children with VI

### Aims

- support parental understanding of their child's development and progress
- identify the small steps underpinning learning stages of readiness, sequence and appropriate goals
- develop a shared language and understanding of development
- provide a common framework
- highlight vulnerable areas that may need further support

## Developmental Journal for Children with VI

### 2 years in development

- Consultation with a range of professionals
- Discussion with over 40 families
  - focus groups
  - national consultation events
  - Developmental vision clinic
  - piloted at home using draft materials



## Developmental Journal Vision record and promotion of vision

Record of Developing Vision

Developing Vision Activity cards  
– visual promotion

## A Parent's view of using the Developmental Journal

*The Developmental journal was introduced at a point when we felt very low - had been devastated and overwhelmed by diagnosis'*

*'Could not see how my son could possibly learn and develop in the same way as his big brother.'*

*'Feel developmental journal is a 'fantastic idea' - it is 'a great tool' that has boosted confidence in my son's ability to learn as well as my ability do the best for him as a mother'.*

*'Support from professional is vital to break it down so that it does not feel 'too much' and to explain why some things are so important. Regular support is needed.*

## Feedback from parents

- Record of achievement / ability to learn
- Development in 'bite sized chunks'
- Greater parental understanding of developmental steps
- Gives practical ideas clearly signposted from developmental goals
- Increases confidence - shows ordinary parenting skills are enough
- parents say they feel that their views are valued
- Encourages a shared language
- Promotes understanding of play as a tool for learning

## Implementation

- Early identification of children with VI
- Early involvement of Specialist teachers for children with VI and/or other professionals
- Training in early child development, VI and in the materials

[www.earlysupport.org.uk](http://www.earlysupport.org.uk)

### Care Pathway for children with VI

- emotional support and information for parents at the time of diagnosis
- immediate liaison with the specialist service for young children with VI
- support from a specialist teacher for children with visual impairment who will introduce the Developmental Journal
- regular support may be delivered by an VI trained early years worker

### Care Pathway for children with VI

#### Paediatric support

- close developmental follow-up and management of associated problems
  - sleep, feeding
  - investigation and cont. management of other possible assoc. medical conditions
- regular review of funct. vision, guidance for promotion of vision and development adapted to the level of vision
- assessment and advice from MDT

Regular ophthalmological follow-up with paediatric ophthalmologist ideally

### Children apparently doing well may also be 'at risk'

Valerie Tadic,  
in collaboration with Linda Pring and Naomi Dale

VI and sighted children matched for Verbal IQ (normal range)

Valerie Tadic, PhD dissertation (in preparation for publication)

### In summary children with VI

At least three subgroups of clinical concern:

- i) Doing well or exceptionally well esp. in language + pragmatic communication and behavioural flexibility difficulties
- ii) Uneven delay + have social communicative difficulties - ASD spectrum
- iii) Developmental setback + clinical autism

### Advisory group of health, education and voluntary sector

John Ford and Elizabeth Andrews - DFES

Eileen Boothroyd

- SENSE

Julie Jennings

- RNIB

Christine Ennals

- Family Support Specialist

Moorfields Hospital

Diana Wingfield

- Head of VI LEA Service Essex,  
ESP Pathfinder

Sue Lewis

- HI monitoring protocol  
Ewing Foundation

Sue Buckley

- Downs Syndrome Research  
Foundation

Patricia Sonksen

- Consultant Paediatrician  
(retired director, Developmental Vision Team)