

The Management of Children with Visual Impairment

Paul Polani Lecture
BACD annual conference 2009

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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 their 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

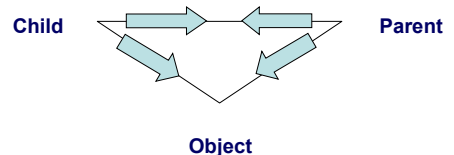
Under 18 mths

No significant differences in social communicative behaviours *

between all visual level groups

*Questionnaire survey (N-74) Dale et al

Joint referential attention

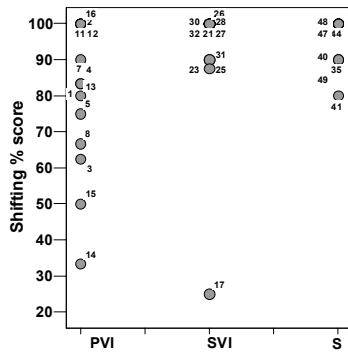


Gaze following, pointing, showing, giving

? 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

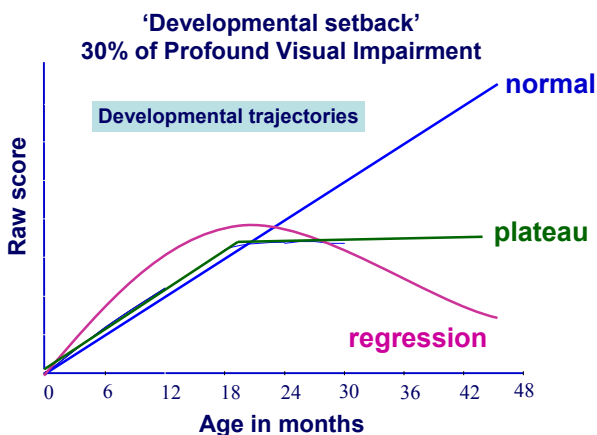
Profound VI (PVI):

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 for Children with VI

- designed to be used by families, or to be family-led in partnership with professional
- complements and supports other forms of professional assistance e.g. formal developmental or visual assessments
- is not a standardised checklist or assessment tool

Contents of Developmental Journal

- Each stage divided into
- five developmental areas (each with different colour and different picture icon)
- Themes
- Developmental goals

Developmental Journal Developmental Areas

- Social and emotional development
- Communication, Language and Meaning
- Play and Learning (including Using hands)
- Movement and Mobility
- Self-Care

Contents of Developmental Journal

- Each theme divided into 'developmental goals'
- shows what child has achieved
- is currently learning
- identifies new goals to aspire to

'Getting stuck' some ideas and suggestions about common problem areas

- Touch sensitivity
- Sound sensitivity
- Repetitive behaviours
- Language Concerns / 'Echolalia' or echoing
- Resistance to adult direction / Tantrums
- Resistance to change
- Learning, social and communication
- Eating and feeding
- Sleeping

Stage 1b - Activity card

Early Support

Card 3 - Play and learning

Making connections

Learning about sound

Understanding what objects are there

Visual environment and visual materials for development and learning - functional vision levels (1 - IV)

Remember to look at the visual environment and visual material cards

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

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)