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WAGR syndrome- a Neurodevelopmental perspective

International WAGR Syndrome Association
9th August 2025

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Consultant Neurodevelopmental Paediatrician
Great Ormond Street Hospital & Moorfields Eye Hospital, London, UK

40 years of Developmental Vision Service

Great Ormond Street Hospital for Children NHS Trust

The Wolfson Neurodisability Service, Great Ormond Street Hospital (GOSH)

Multidisciplinary team: paediatricians, psychologists, occupational therapist, speech and language therapist

Comprehensive assessment and guidance to optimize visual and developmental potential and outcome

Early years' programme (0-5) plus older children

Integrated clinical and research programme

Over 4000 children on database

[Developmental Vision Clinic | Great Ormond Street Hospital]

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Impact of VI on development

Visual impairment may constrain development of:
Motor skills, language and communication, emotional bonding, cognitive skills
Increased risk of early social communication difficulties and autism
Development ≠ sighted child ‘minus vision’
Behaviours/difficulties which are *specific to* VI
Specific or generalised cognitive difficulties

Reynell and Zinkin 1975, Sonksen 1979, Sonksen et al 1984, Sonksen 1993, Sonksen & Kingsley 1995(Dale,Sonksen,2014)(Dale and Salt 2017)

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Who we see

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- Young children with congenital eye disorders and genetic eye disease
- Babies and young children with VI-multidisability
- Children with known Cerebral Visual Impairment to provide vision and developmental assessment to clarify such difficulties and their impact in further detail
- Older children with ‘isolated’ VI with concerns about social skills/interaction, or educational progress.
- Neurological disorders with significant visual disorders

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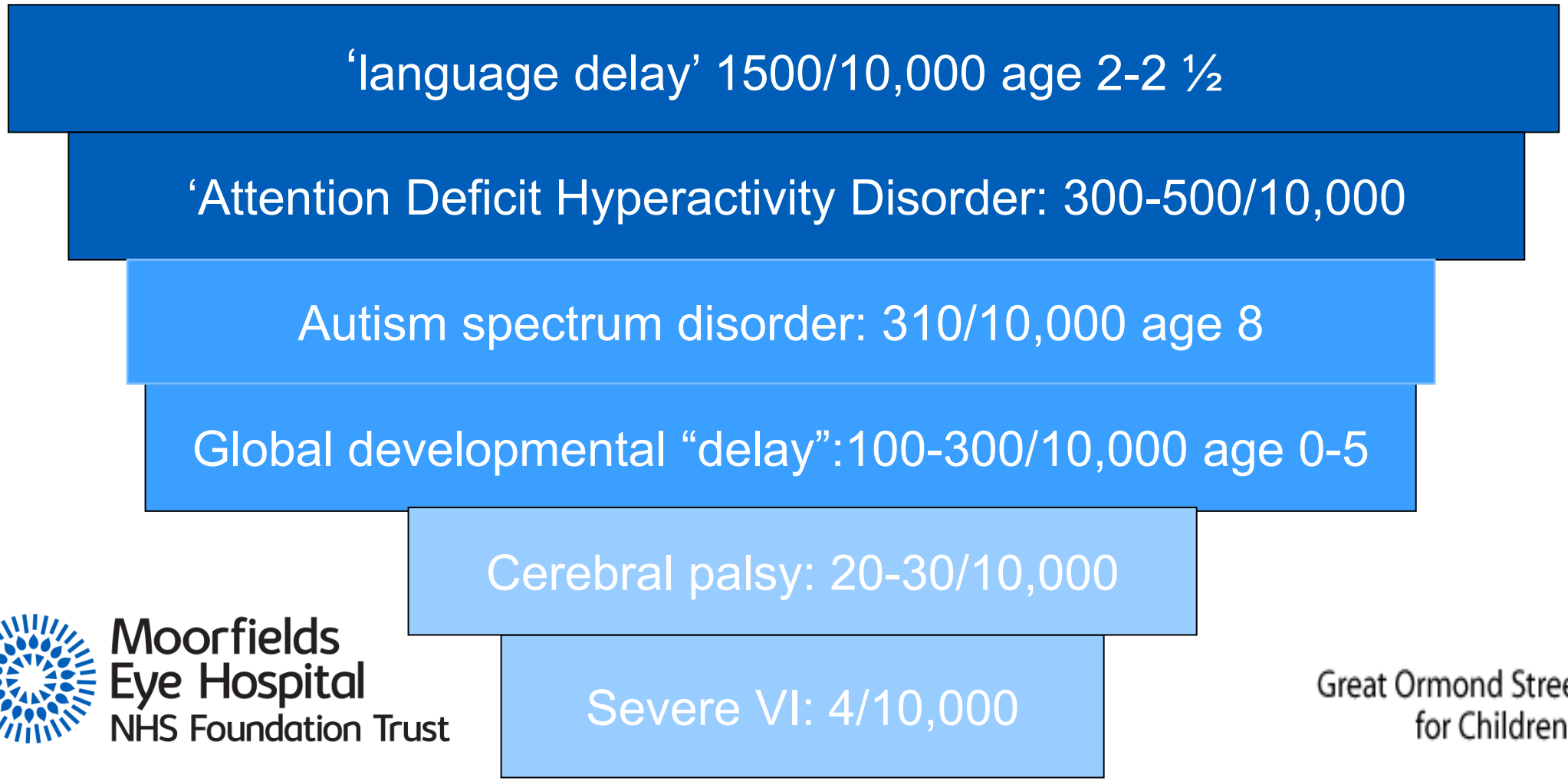
Childhood Developmental Difficulties



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Multidisciplinary team

Gastroenterologist

Parents& wider family

Teacher

Speech & lang therapist

Respiratory physician

RESPITE

Nephrologist

Nursery & portage worker

Specialist teacher

Audiologist

Surgeons

Physiotherapist

Paediatricians

Community services

Geneticist

GP

Ophthalmologist and Eye clinic staff

Occupational therapist

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Challenges of clinical and research work in children with VI

- complex and heterogeneous rare population
- expertise required to work with infants and children with VI
- adapted assessment tools and techniques needed (tools for sighted children unsuitable)
- uncertain prognosis and many factors influencing vision and development
- parents and local therapists felt very uncertain how to help

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Vision tutors sound localisation and understanding

Sounds and objects are linked

Sounds have substance in space

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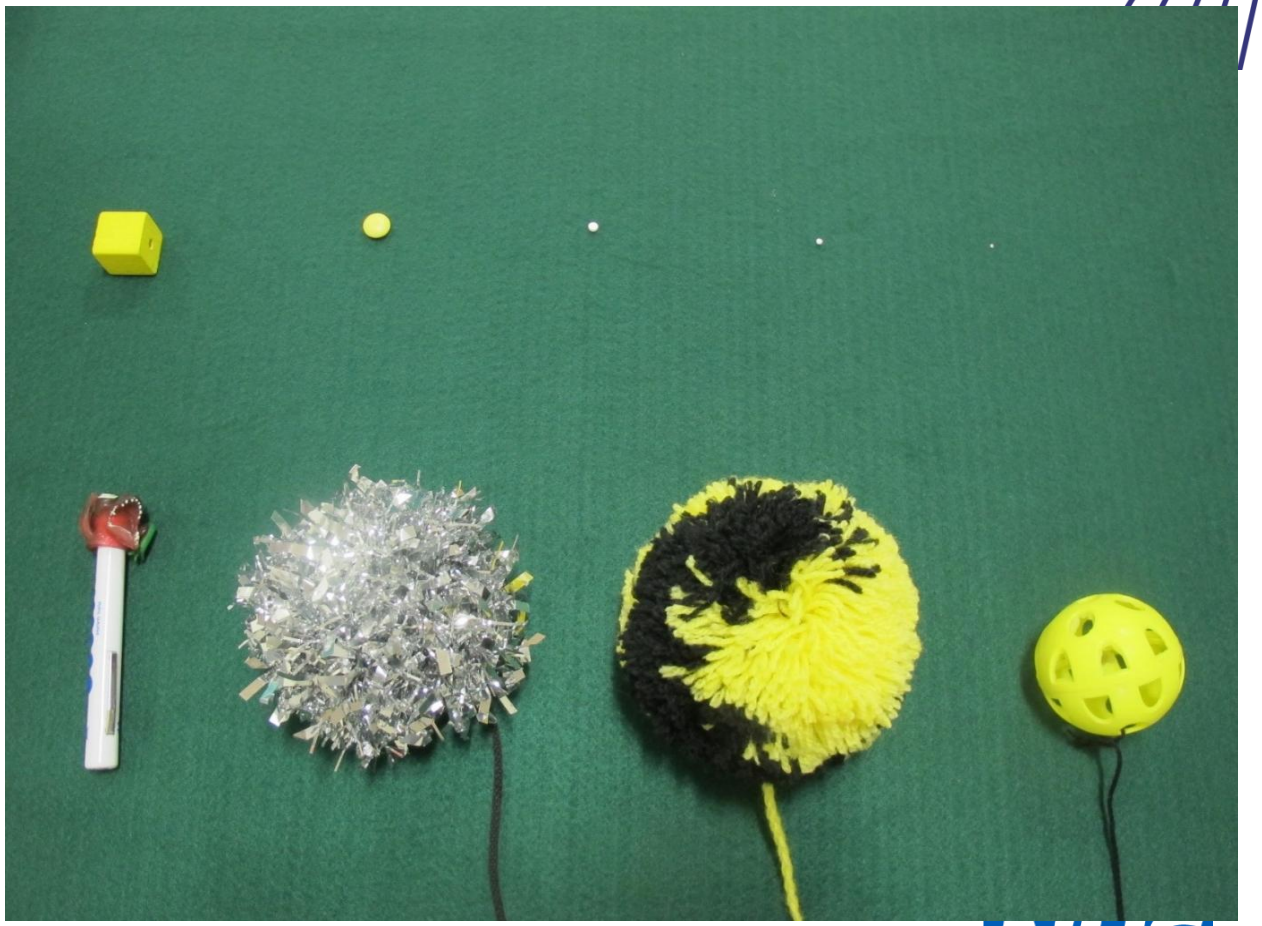
Measuring low levels of vision

Glowing torch in dim light

Profound visual impairment: Light awareness

Near detection scale



Severe levels of visual impairment: can detect form

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Sonksen LogMAR test of Visual Acuity

Tests for Distance and Near Acuity with preschool norms

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Salt A, Wade A, Proffitt R, Heavens S, Sonksen PM
The Sonksen logMAR Test of visual acuity: I. Developmental compliance and reliability JAAPOS Dec 2007

Sonksen PM Wade A, Proffitt R, Heavens S, Salt A The Sonkser Test of visual acuity: II
Age norms from 2.9 to 8 years, JAAPOS Feb 2008

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Gross detection vision- 12.5 cm ball

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Gross and Near detection vision

6.25 cm ball at 30 cm

1.25 cm – 3mm object at 30 cm

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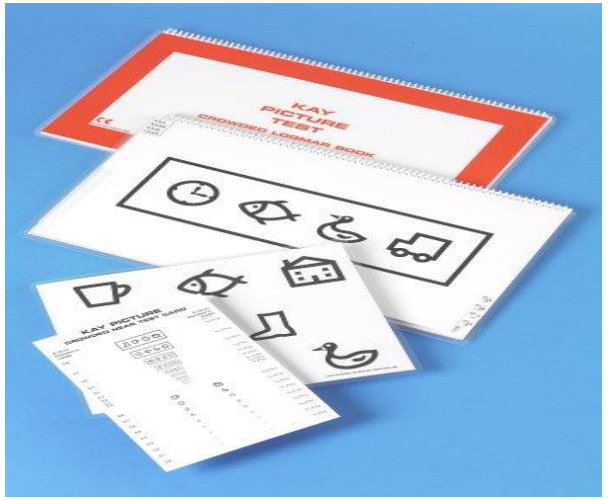
Standard” measures of visual acuity in children

Grating acuity Cards



Kay Picture test

Cardiff Acuity test

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Vision for everyday objects and pictures

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Reynell Zinkin scales for Visually Impaired Children – Infancy to 5 years

- Sensorimotor understanding
  Understanding of concrete objects/their relationships
- Response to sound and verbal comprehension
  Listening, localising, recognition
- Vocalisation and expressive language (structure)
  sounds, words, sentences
- Expressive language , vocabulary and content

- Object naming, object function, action descriptions

- Also report on free play, behaviour, social communication

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Joan Reynell and Pam Zinkin 1975, 1979
Dekker, Drenth & Zaal 1988
Dale et al, 2017

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Reynell Zinkin Scales

RECORD FORM

Reynell-Zinkin Scales: Developmental Scales for Young Visually Handicapped Children

Chronological age:

Visual Category

Full vision: (Sighted)

Some vision: (Partially sighted)

No Vision: (Blind)

Sub-scale	Raw Score	Age Equivalent
Sensori-motor Understanding		
Response to Sound and Verbal Comprehension		
Vocalisation & Expressive Language (structure)		
Expressive language, vocabulary and content)		

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Reynell Zinkin developmental assessment
Verbal comprehension scale

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Reynell Zinkin Developmental assessment
Expressive language scale-actions/ descriptions

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Reynell Zinkin Scales: Age Norms corrected for vision levels

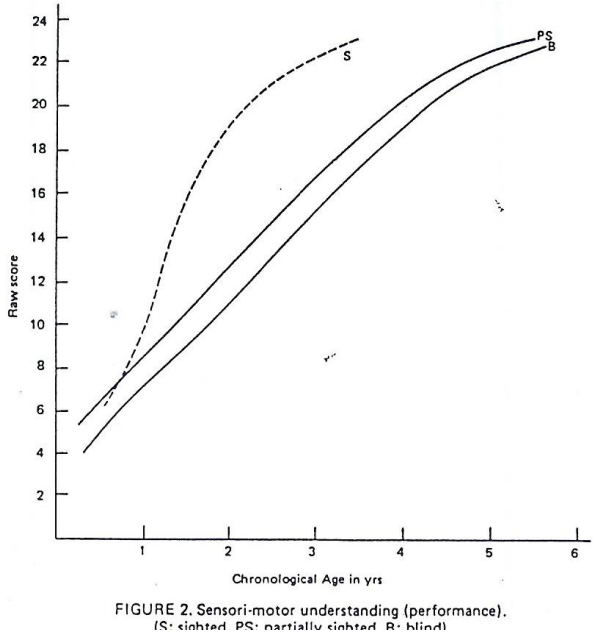

FIGURE 2. Sensori-motor understanding (performance).
(S: sighted, PS: partially sighted, B: blind)

Sensorimotor understanding

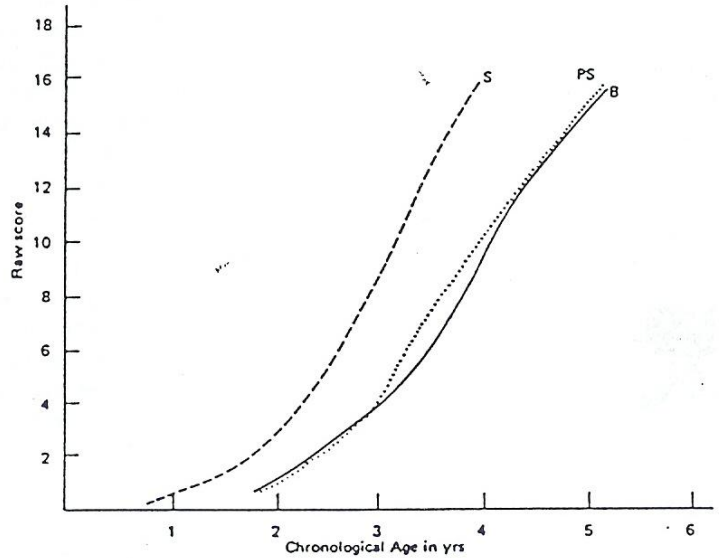

FIGURE 6. Expressive language, (b) language content

Language comprehension

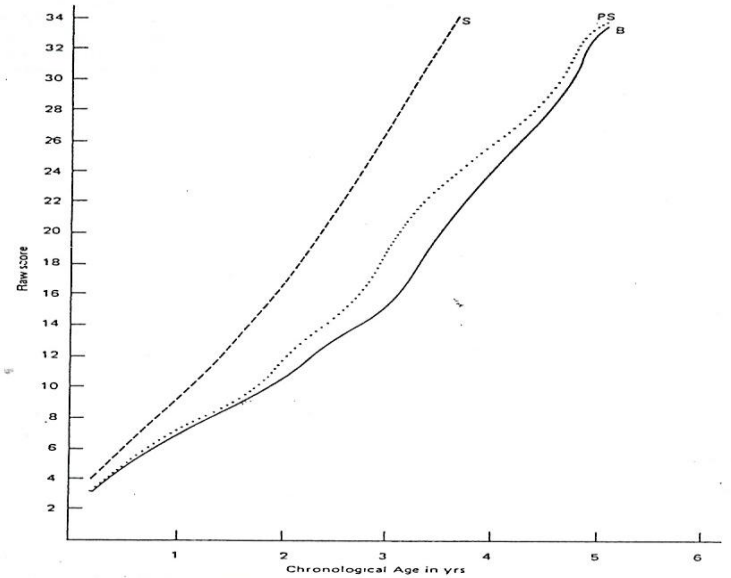

FIGURE 4. Response to sound and Verbal comprehension.
(S: sighted, PS: partially sighted, B: blind)

Language expression

Mean delays of up to 12-24 months

Blind < partially sighted < sighted

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Reynell J (1978) Developmental patterns of visuall Child: care, health and development. **4:** 291 - 303.

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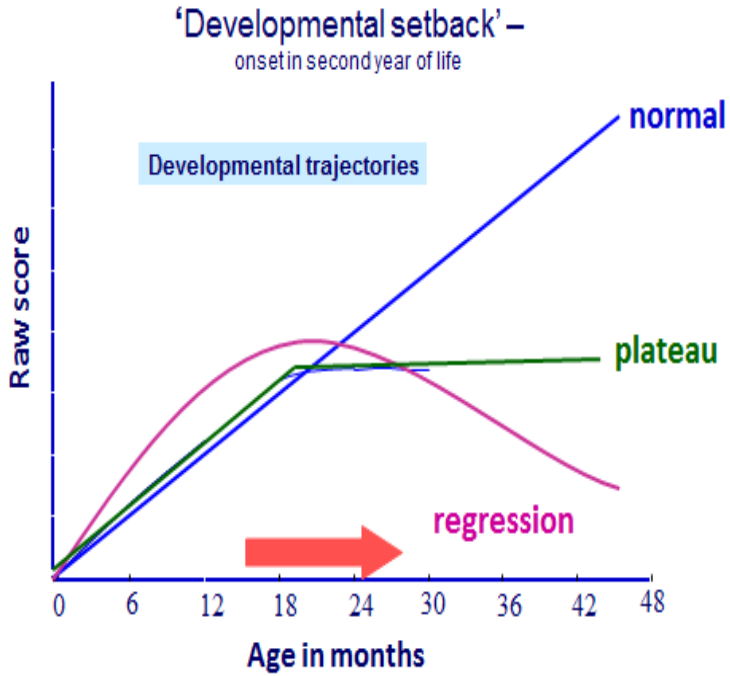
Difficult areas

Some show early plateauing or regression : ‘setback’ (30%)
Some show persisting difficulties
Some may ‘catch up’ after pre-school period
BUT need support with mobility, social rules, literacy,
Braille learning presents additional challenges
Higher rates of fatigue and reduced mental well being
Specific learning difficulties may also occur
Risk of ASD much higher than in sighted population – irrespective of early developmental patterns



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Difficult areas

- Reluctance to touch, resistance to guidance
- Feeding – poor tolerance of lumps/tastes
- Talks in sentences but not functional
- Play skills less well developed than language skills
- Repetitive movements/rigid in play but can show good play skills when encouraged
- Sleeping difficulties

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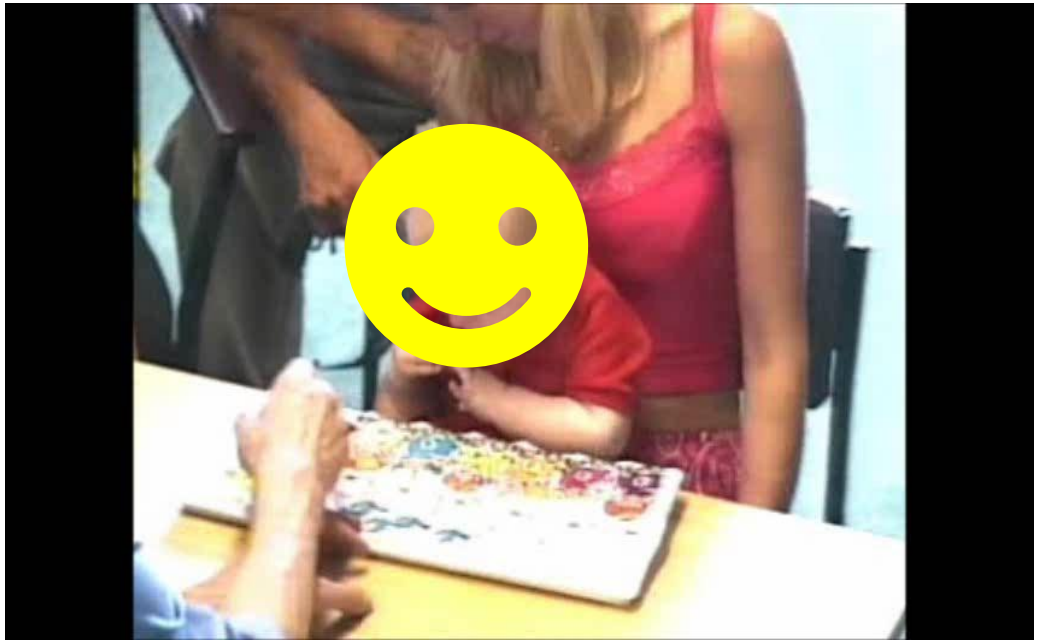
Learning about the world

Hands stay passive or avoid touching things
-Limits object exploration
-Further limits sensory input to brain

Unable to localise sound (can't see source)
- May delay reaching and grasping objects



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Difficulties shifting attention to new activity
Behavioural rigidity

Can’t establish joint attention through vision, can’t establish actions others, limitation in play.

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Targeted vision and developmental advice provided

Promoting “looking” behaviours

- What does the baby alert to and how can that be promoted ?
- Going from visually **alerting** to an object/ person to improving visual **attention** with the aim of promoting increasing visual **interest** and **curiosity**
- Helping the child to use their vision to their best during the crucial period of development

Next step-always the next step

-Localising sounds in all directions and reaching out

-Using hands to explore and learn

-Vocalising and turntaking

-Anticipation and requesting “more”

-Joint / shared attention and play

- Commenting on things the child does and on their play

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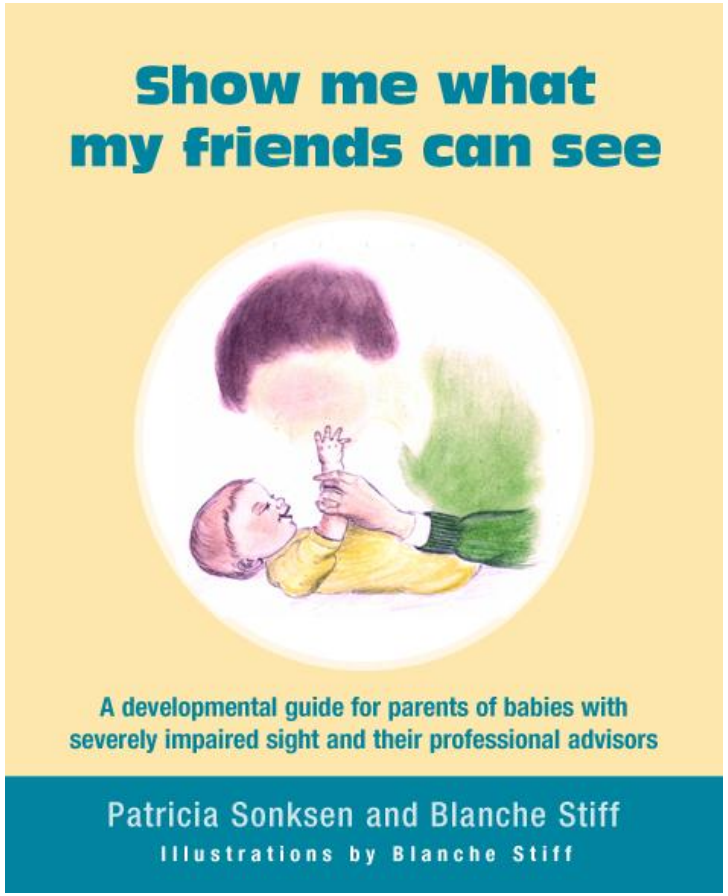
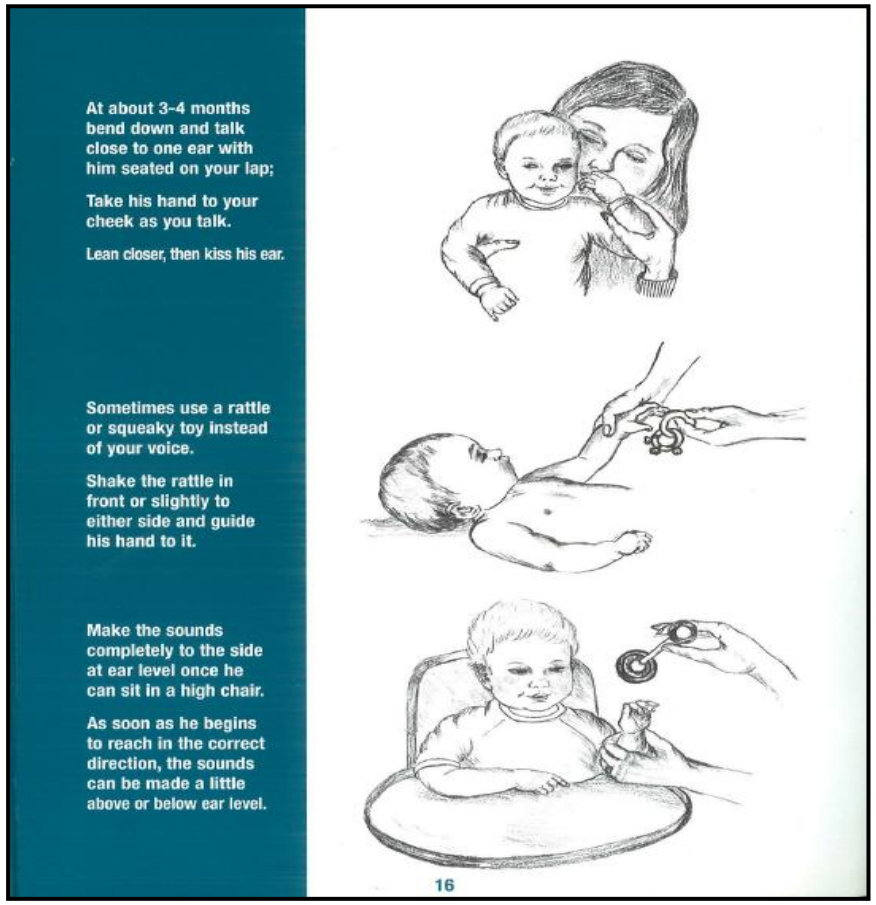
Practical guidance for parents





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Developmental Journal for babies and young children with visual impairment (DJVI)

- Support from earliest concern of VI (0-3 years)
- Rapid coordinated referral route (Ophthalmology to QTVI)
- Promotion of vision
- Promotion of development
- Include focus on vulnerable processes
- Structure and monitor intervention and support progress

DJVI- 1st Ed 2005, Salt A, Dale N, Osborne J – DfES, UK, DJVI- 2nd Ed 2017, Salt A, Dale N

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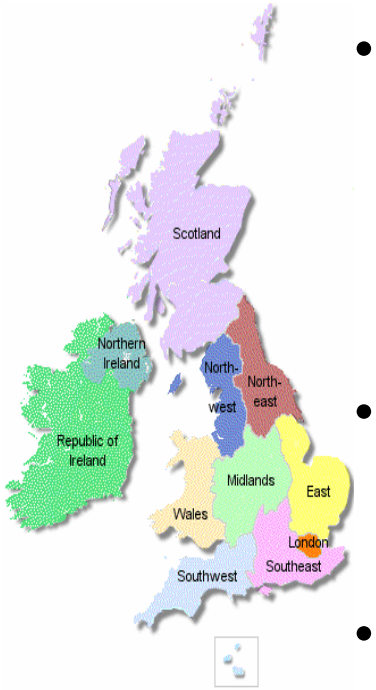
National projects

OPTIMUM project: 2011-2016

- National UK study
- 100 infants
- Longitudinal study
- Followed from 12 m to 3 y
- Included evaluation of Developmental Journal



Key outcomes from Optimum

- Early intervention using the Developmental Journal in a structured manner showed better outcomes compared with those receiving 'other' support
- Use of Developmental Journal impacted positively on parenting stress
- Parenting stress higher in parents of children with the lowest levels of vision

NIHR | National Institute for Health Research

Fight for Sight
Pioneering eye research

RNIB
supporting blind and partially sighted people

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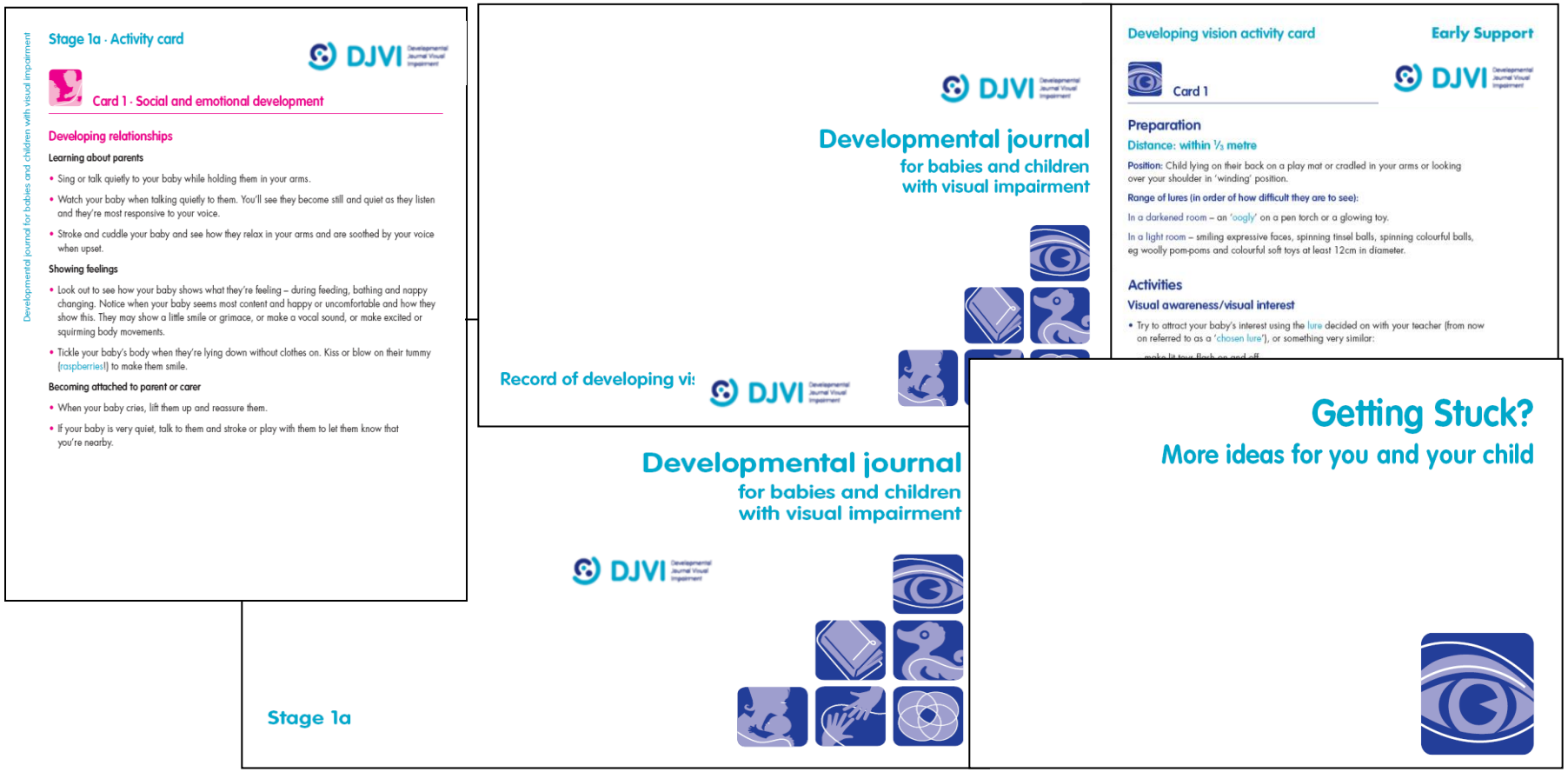
Dale NJ et al, Dev Med Child Neurology 2019, 61(6), 697-709
RNIB policy document- Young Vision Alliance, EYPS 2020
Royal College of Ophthalmologists, Paediatric subcommittee, 2012

Developmental Journal for Babies and Children with visual impairment



Licensing information:
https://xip.uclb.com/i/healthcare_tools/DJVI_professional.html

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DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY ORIGINAL ARTICLE

Home-based early intervention in infants and young children with visual impairment using the Developmental Journal: longitudinal cohort study

NAOMI J DALE[1,2] | ELENA SAKKALOU[2] | MICHELLE A O'REILLY[2] | CLARE SPRINGALL[1,2] | HANNA SAKKI[2] | SARAH GLEW[2] | ELENI PISSARIDOU[2] | MICHELLE DE HAAN[2] | ALISON T SALT[1,2]

1 Neurodisability Service, Great Ormond Street Hospital for Children NHS Foundation Trust, London; **2** Clinical Neurosciences, UCL Great Ormond Street Institute of Child Health, London, UK.

Correspondence to Naomi J Dale at Great Ormond Street Hospital for Children, Great Ormond Street, London WC1N 3JH, UK. E-mail: n.dale@ucl.ac.uk

54 children had full child datasets (T1, T2, T3) and full practitioner datasets (38 had 'simple' CDPVS)

Clinically relevant improvements in sensorimotor understanding/cognition and expressive language (structure) and significant reduction in behaviour and parenting stress in children and parents receiving the Developmental Journal (cf other home visits)

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Cognitive and other Assessments

- Child reaches ceiling on RZ scales: verbal subtest of Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III) 3rd Edition
- Over 4 ½ years: Wechsler Intelligence Scales for Children V edition (WISC-V) - may use only verbal test depending child's level of vision
- Intelligence Test for Visually Impaired Children (ITVIC)
- Language
- Functional / self help skills/ sensory profiles
- Social communication, specific learning difficulties, ADHD etc

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Neurodevelopmental Disorders - Development is complicated!

- Intellectual disability
- Global developmental delay
- Language disorder
- Speech sound disorder
- Autism Spectrum Disorder(ASD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Specific learning disorder/ dyslexia
- Developmental coordination disorder
- Movement disorder
- Tic disorder

Biology

- Genes
- Epigenetics
- Other

Environment

Interaction between biology and environment

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Diagnostic and Statistical Manual of Diseases- 5th Edition (DSM V

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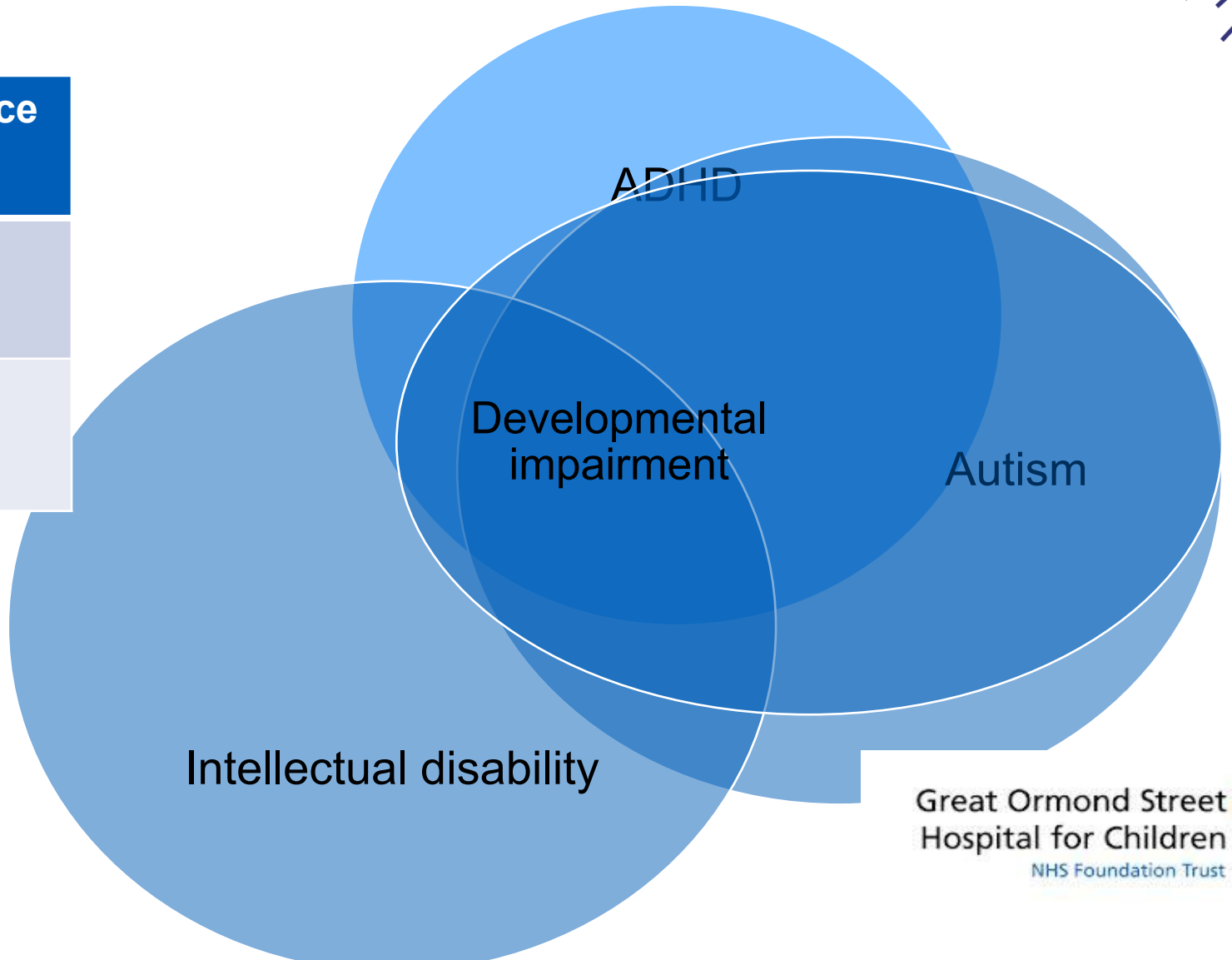
These difficulties can occur together

Co-morbidity with ADHD	Incidence
ASD	65-80%
Intellectual Disability	15%



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Assessment of neurodevelopmental difficulties

- Ideally multidisciplinary- Paediatrician/ Psychiatrist/ Psychology/ Speech and Language therapist, Occupational Therapist
- Information obtained from parents, nursery, school, college, young person
- Perinatal and past medical history
- Targeted developmental history focussing on the known criteria for diagnosis
- Family history
- Enquiry about other difficulties/ sleep/ eating/ selfhelp skills/ community participation/ mood etc
- Standardised questionnaires and assessments- adapted for VI
- Physical and neurological examinations and investigations

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Autism Spectrum Disorder (ASD)

- Impairment of Social Interaction and Communication
- Restricted, repetitive patterns of behaviours, interest and activities
- Unusual responses to sensory stimuli
- Impact on child's home, school, leisure
- Impact on family

- Multifactorial
- Heritability
- Neurologic changes – pre natal and early postnatal
- Genetic factors
- Brain differences

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ASD in children with VI

Social and communicative vulnerabilities include autism symptomatology from infancy

-Response to subject's own name, social referencing , social communicative behaviours,

-Restricted interests and stereotyped behaviours

Prevalence rates of 30% Autism, 60% ASD range

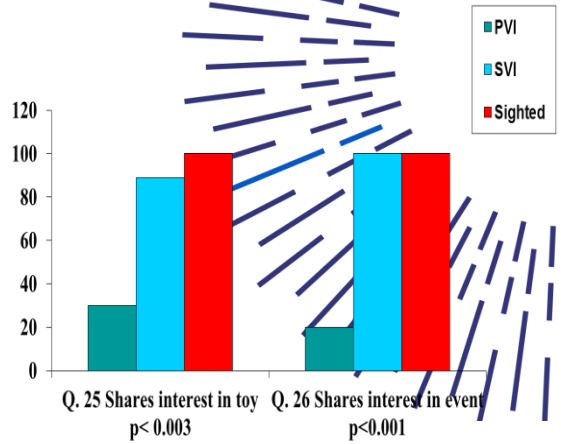
Risk ratio of 31.0 of general population, Do et al 2017

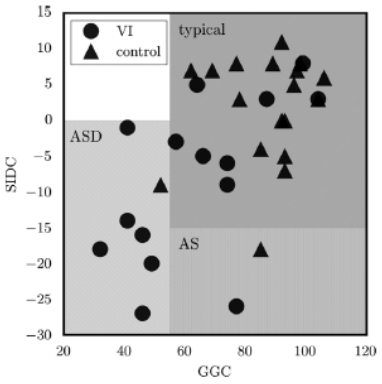
Causal factors

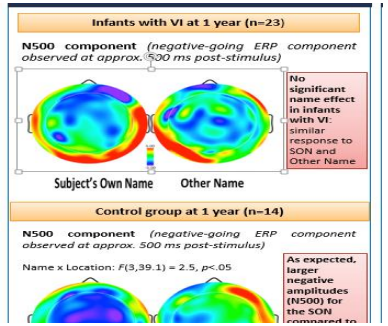
-eye genes expressed in brain vision deprivation on social brain networks

-*eg SOX2, PAX6, CEP290*

-environmental –child interaction and learning







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Parr et al 2010 Dev Med Ch Neurology, **Absoud et al** 2011 Dev Med Ch Neurology,
Dale et al 2014, Child: care health and dev **Bathelt et al** 2017 Dev Cognitive Neuroscience, ***Do et al** 2017 Ophthal Physiology

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Autism Spectrum Disorder

Impairment	Mildest form	Most severe
Social recognition	Poor grasp of rules of social interaction and lack of perceptiveness towards others	Aloofness and indifference
Social communication Language	Language but no true reciprocal conversation Longwinded, literal and pedantic	Absence of any desire to communicate No language
Social imagination and understanding Special skills	Cognitive awareness of others feelings and emotions but no empathic sharing of emotions Well above age expectations	Total absence of copying and play Absent
Repetitive patterns of behavior Mannerisms and sensory responses	Repetitive questioning Minimal or absent	Self injurious behaviours Very marked

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Social communication assessment

- Cognitive (general knowledge) assessment
- Language and functional assessments
- Play based (modified ADOS) assessment
- Ongoing work in adapting standardised assessment
- Questionnaires and observations
- Recommendations- targeted to the childs developmental profile

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Attention Deficit Hyperactivity Disorder (ADHD)

- Prevalence:5% in paediatric population
- Prevalence up to 15 % in childhood VI population
- Hyperactivity(Motor restlessness)- fidgets, on the go, runs, climbs out of car seat, cot, can't sit
- Impulsivity- blurts out, can't wait their turn,
- Inattention-doesn't seem to listen

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ADHD- WHAT'S HAPPENING IN THE BRAIN?

Frontal Lobes

- Pay attention to tasks, focus, plan
- Anger, frustration, irritability

Inhibitory Mechanisms of the Cortex

Limbic System

- Emotions , arousal

Reticular Activating System,

Changes in Dopamine transport gene

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After assessment- what next?- our practice

- Feedback profile of strengths and weaknesses within the context of a diagnosis/ diagnoses
- No two children or young people are the same
- Impact of the family, school environment community support cannot be underestimated.
- Report with recommendations and signposting to services
- Encourage parents to meet with GP/ Local Paediatrician/ School to discuss the report
- Education and health care plan - updated
- Opportunity to speak about sibling support/ young carers/ respite/ medication management

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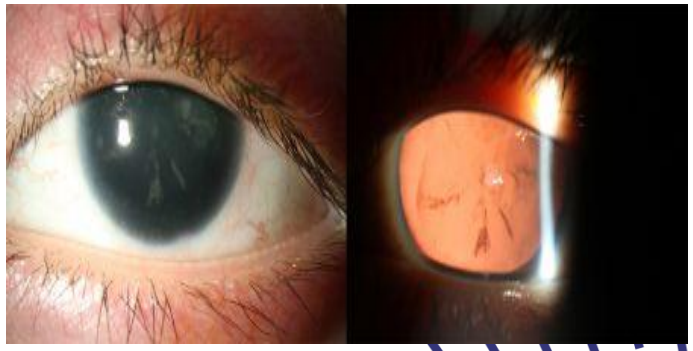

Exploring neurodevelopmental phenotypes in children and young people with *PAX6* related aniridia-a preliminary analysis

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Methodology

Case note review and screening questionnaires completed by parents

Inclusion: Children aged 4.5-15.5years

Exclusion: Children with additional genetic mutations or chromosomal rearrangements

Goodman's Strengths and Difficulties Questionnaires (SDQs)

Social Responsiveness Scale Questionnaires - 2nd Edition (SRS-2).

Visual acuity was recorded as LogMAR at their closest clinical visit

Results

18 children met criteria.

4 families were uncontactable.

2 did not return questionnaires.

12 children
M:F-8:4 (2:1).
Mean age 10.1 years
(Range 4.5-15.5 years)

Ethnicity
9 White British
1 Black African
1 Croatian
1 Romanian

Visual acuity
Moderate-severe
(LogMAR 0.86-1.1).

Frameshift, nonsense, missense and intronic *PAX6* variants were represented

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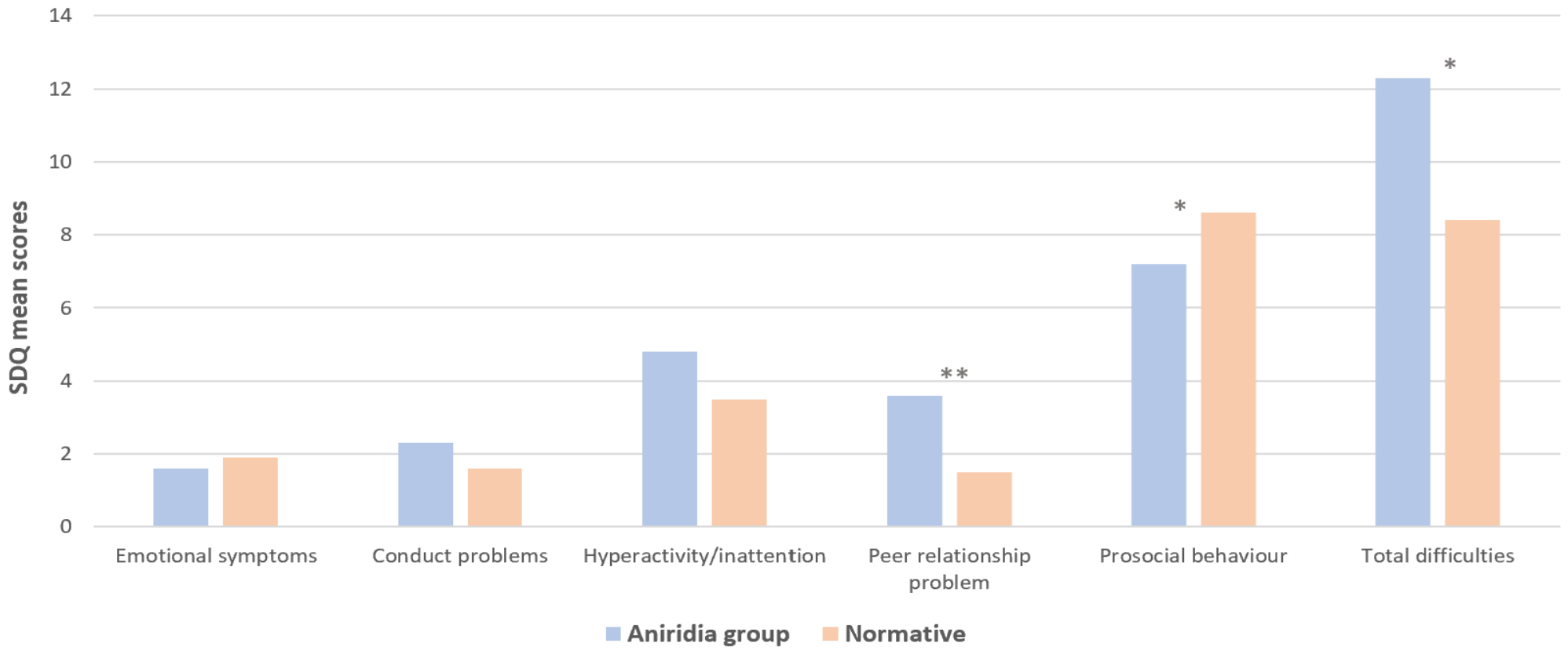
SDQ-mean scores



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** = statistically significant at <0.001, *= statistically significant at <0.05

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SDQ's-mean scores

SDQ Subscales	*PAX6* Score (N=12)	Percentage of parents (N=12)	Normative score (N=10,298)	P-value
Emotional symptoms	1.6	50 %	1.9	0.29
Conduct problems	2.3	58%	1.6	0.07
Hyperactivity	4.8	58%	3.5	0.10
Peer relationship problems	3.6	67%	1.5	< 0.001*
Prosocial behaviours	7.2	75%	8.6	< 0.002*
Total difficulties	12.3	50%	8.4	< 0.01*

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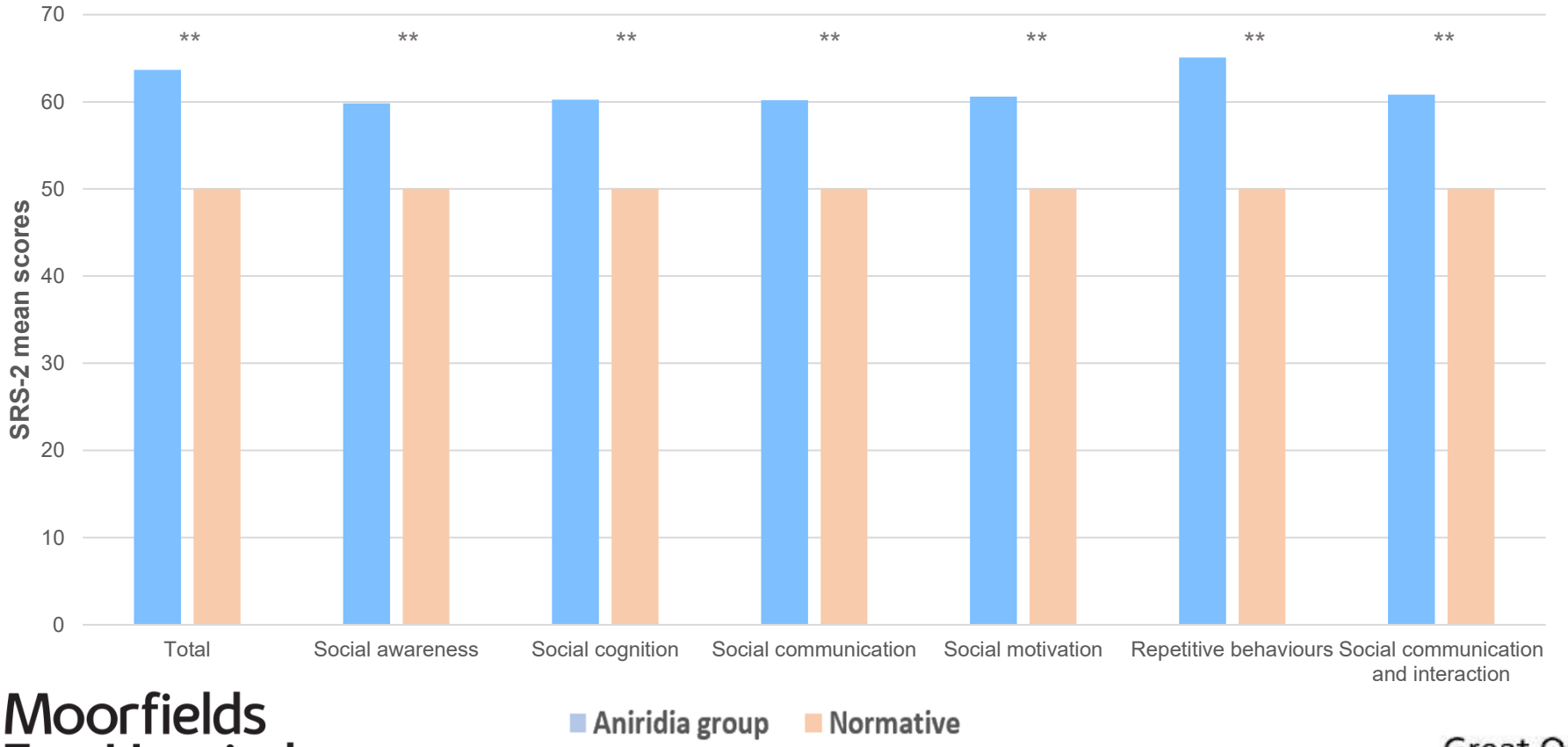
SRS-2mean scores



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** = statistically significant at <0.001

Additional reported parental concerns

	ADHD on medication	Learning difficulties	Anxiety and Depression, suicidal ideation
Boys (8)	3	3	1
Girls (4)	1	1	2
Total (12)	**4 (33%)**	**4 (33%)**	**3 (25%)**

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Secondary analysis of parent rated scores

No correlation between visual acuity measures with domains on either questionnaire

No statistically significant differences were observed between the gene variants

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CONCLUSION

- Children with *PAX6* related aniridia appear to be at increased risk of neurodevelopmental disorders than their sighted peers even when the effects of visual impairment are accounted for
- Additional of mental health and learning and intellectual difficulties are present
- Larger studies are required to further quantify genotype-phenotype correlation.

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Behaviours- what's going on?

A- antecedent- what preceded the behaviour

B- What is the behaviour?

C- Consequence- reinforce Vs extinguish

Behaviours have got to be understood

Early referral to CAMHS/ Community Paediatrics

What is the child's profile?

- cognitive ability
- more behavioural difficulties with developmental impairment and intellectual disability

What is the child's understanding of others language and communication?

- Is there autism?
- Are there sensory differences / anxiety
- Is there ADHD?
-

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Behaviours

- Important to have conversations with your GP about early difficulties so that Community Paediatricians and schools can get involved to support. As a teaching hospital, we liaise closely with the local services at the point of diagnosis with recommendations for ongoing support or input.
- Important that the behaviour is understood for what it is using an ABC approach
- -the antecedent (what led to the behaviour)
- - the behaviour itself- hitting/ spitting/ biting/ throwing
- - consequences- did they extinguish/ reinforce these behaviours?

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Autism and anxiety

Cause of anxiety

- Difficulty recognising emotions of self and others
- Sensory sensitivities
- Difficulty with uncertainty
- Performance anxiety

Behaviours seen

- More repetitive in their actions
- They may spend more time on hobbies and interests
- They may become more insistent on routines, as a way of managing uncertainty, fear of failure and sensory input.

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Once the “behavioural” diagnosis is made- follow up with the appropriate management.

Resources in the UK and Europe- will differ from one borough to the other and from country to country
Stretched services in the UK-Local CAMHS
Schools- SLT/communication aids

ADHD- nice guidelines, local guidelines and support systems
ASD- national autism society- www.org.uk

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Support for C & YP with Neurodevelopmental differences and WAGR

- Recognition of the profile of difficulties at school/ college and adaptations and allowances made
- Strengths recognised and celebrated
- Difficulties supported
- Young people “owning” their differences and feel relieved to know they are not the only one with a difference
- Parental support crucial
- National and local ASD/ ADHD/ ID groups
- RESPITE
- SIBLING SUPPORT

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YOUR QUESTIONS

Behaviour–What are a few things that parents can do to prepare for appointments with their children's doctors to discuss behavior problems/issues?

What information is important to share?

Videos of behavior we are concerned about?

Notes we take that describe behaviors and possible triggers or the situations that spark the negative behaviors?

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YOUR QUESTIONS

For parents that are hesitant to use medication to “help” their children, what advice can you give? (for ex: mental health needs to be treated like we would treat any other disease?)

Is there a questionnaire that can be used to share with doctors when trying to explain poor or inappropriate or aggressive behaviors?

Why do some children seem to have more negative behaviors and meltdowns (and aggression when they reach puberty

YOUR QUESTIONS

How can schools and teachers be better equipped to support children with aniridia in the classroom?

What can we do practically to help our child maintain visual function as long as possible?

Development of our WAGR teens. What should we look for and be prepared for? And how can we help our children

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YOUR QUESTIONS

- What are the most common behavioural challenges you see in children with WAGR syndrome?

A-behaviours related to the ID, autism, ADHD

- Are there any early warning signs of anxiety or depression we should be aware of in teenagers with WAGR?

A- Irritability, school refusal, withdrawal, crying, self harming

- How can we support siblings of children with WAGR who may feel overlooked or struggle with their sibling's behaviour?

A- maintaining communication / get help/ let schools know that the child is struggling/ sibling carer networks-

https://www.scope.org.uk

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YOUR QUESTIONS

Mine really comes down to anxiety I believe.
20 questions before we've even said good morning and unable to answer the first one. Nail biting and toe picking included.

A: There may be underlying autism, ADHD, anxiety and depression, sensory difficulties?

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Moving on and succeeding in life

Ongoing Educational support
Social integration and growing up
Advocacy
Mental health support
Transition to adult services

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