Cynulliad Cenedlaethol Cymru | National Assembly for Wales
Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and
Education Committee
Y 1,000 diwrnod cyntaf | First 1,000 Days

FTD 17

Ymateb gan: RNIB Cymru (Sefydliad Cenedlaethol Brenhinol y Deillion) Response from: RNIB Cymru (Royal National Institute of Blind People)

- RNIB Cymru welcomes this opportunity to contribute to the Children Young People and Education Committees consultation into the first 1000 days.
- 2. We provide support, advice and information to people living with sight loss across Wales, as well as campaigning for improvements to services and raising awareness of the issues facing blind and partially sighted people.
- 3. It is estimated that there are over 100,000 people living with sight loss in Wales. This is predicted to double by 2050. It is estimated that there are 1,935 children and young people aged 0–25 with a visual impairment in Wales. At least 20 per cent of these will have additional disabilities and/or special educational needs; a further 30 per cent have very complex needs.
- 4. We welcome the Committee's consultation on the extent to which Welsh Government policies and programmes support the early parent role, as we know that the First 1,000 Days of a child's development are accepted to be the most significant in a child's development.
- 5. Approximately two thirds of children with severe vision impairment (VI) and blindness are diagnosed before their first birthday (1). The single most common cause of VI in children is cerebral visual impairment. It accounts for up to 48 per cent of blindness and between 32 per cent and 45 per cent of all VI in children (2and 3).

- 6. Children at most risk of severe VI or blindness are those who are born pre-term and of very low birth weight, from socio-economically disadvantaged backgrounds, or of South Asian origin (4 &5).
- 7. We believe that Welsh Government should adopt two indicators in the Wellbeing of Future Generations (Wales) Act 2015 which would be useful to monitor for children with sight loss: habilitation support and Qualified Teacher for Visual Impairment (QTVI) coverage.
- 8. Children with sight loss require specialist support to learn vital life skills such as safe movement and orientation. Without that support, they cannot lead healthy lives because they don't have the same freedom of movement as sighted children.
- 9. They are therefore more likely to be socially isolated and denied the opportunities that other children experience to learn and grow in confidence and will be less employable, more dependent on others and less able to contribute to society.
- 10. We know there is a high prevalence of blindness and partial sight in children with learning disabilities [6] although currently in Wales there is no breakdown of information showing the number of children and young people with learning difficulties and vision impairment.
- 11. The UK National Screening Committee (UK NSC) is responsible for reviewing screening policies and making recommendations to ministers in each of the four UK countries about whether or not a screening programme for certain conditions should be set up. Screening procedures for vision are set out in the National Screening Committee Child Health Sub-Group Report on Vision Screening. (7)
- 12. All newborn and 6-8 week old babies should be examined as part of the routine review to exclude retinoblastoma, glaucoma and cataract since they are treatable and, respectively, life and sight threatening.

- 13. Infants and young children with VI show developmental delays compared to sighted infants and are at greater risk of social communication, attention and behavioural difficulties (8 &9). If babies with a VI are not identified early and intensive health and education developmental support provided in the first two years of life, the development of the child's social and communication skills can be seriously impeded [10]. Blind children, in particular, require high levels of specialist input to address crucial needs in their cognitive development, communication, social and independence skills [11].
- 14. The first year of a child's life is also extremely important in the development of the visual system and so if problems are not identified early enough, there can be permanent effect on a child's eyesight, hence early diagnosis and prompt treatment is essential.
- 15. Vision is a major source of information that helps us to learn most estimates suggest that vision provides about 80% of the information we need. The eye is the most developed organ of the body at birth and it develops more quickly than any other immediately after birth.
- 16. The needs of children diagnosed with ophthalmic disorders will vary substantially according to whether these are isolated or part of a complex of other impairments or diseases, as well as by the level of visual loss experienced.
- 17. The person, who can help parents most locally, is a qualified teacher of children and young people with vision impairment (QTVI,) based in the local VI service. They will support parents and child from birth onwards and referral should be automatic from the eye clinic.
- 18. Children with vision impairment face unique challenges to learning which can only be addressed by specialist knowledge and understanding. We believe that all blind and partially sighted children and young people must receive specialist support from a QTVI.

- 19. QTVIs hold the mandatory qualification (MQ) in vision impairment, in addition to qualified teacher status.
- 20. Evidence shows that the QTVI is usually the key worker for a blind child, assessing their needs and co-ordinating the provision to address these.
- 21. QTVIs carry out a central role in the education of children and young people with vision impairment from birth, working in homes, early year's settings, schools and post 16 settings.
- 22. Whilst we are aware of good practice in the deployment of QTVIs nationally, we also know that there are a number of concerns about the service which include significant budgetary pressure on local authorities, insufficient numbers of trained, qualified and experienced, staff to meet the support needs of the reported caseload and a lack of spare capacity in Wales.
- 23. All specialist teachers of working age are currently employed by specialist LA services or within resource bases and there is no access to supply cover should a specialist teacher be on sick or maternity leave.
- 24. This means that an All-Wales solution is needed for recruitment, training and maintaining the workforce.
- 25. The qualification for teaching children with a visual impairment is mandatory in England. The only university which run the course in the UK is in England (Birmingham) and therefore Welsh teachers are not regarded as the priority to study.
- 26. Furthermore, even if the qualification is made mandatory at some point in the future, it is vital that inspection regimes ensure that specialist support is being provided across Wales now.

- 27. We believe that Wales should have a mandatory qualification route that has a Welsh focus, is competency / skills based and fits with national service and delivery specifications.
- 28. It is also important to ensure that the Welsh language is emphasised within the training and that the qualification is portable across the Wales/England border

References

- (1). Rahi and Cable (2003) 'Severe visual impairment and blindness in children in the UK' **The Lancet**, Vol 362, Oct 25, 2003
- (2) Mitry, Bunce, Wormald and Bowman (2013) 'Childhood VI in England: a rising trend'. **Archives of Disease in Childhood** 2013; 98: 378-380.
- (3) Mitry, Bunce, Wormald, Leamon, Simkiss, Cumberland, Rahi and Bowman (2013) Causes of certifications for severe sight impairment (blind) and sight impairment (partial sight) in children in England and Wales. **British Journal of Ophthalmology** 2013; **97**: 1431–1436.
- (4) . Hamblion, Moore and Rahi (2012) 'Incidence and patterns of detection and management of childhood-onset hereditary retinal disorders in the UK. **British Journal of Ophthalmology** 2012, 96: 360-365
- (5). Solebo and Rahi (2014) Epidemiology, aetiology and management of visual impairment in children. **Arch Dis Child** 2014, **99**: 375-379
- (6) Das, Spowart, et al (2010). 'Evidence that children with special needs all require visual assessment.' **Archives of Disease in Childhood** 95(11): 888-892.
- (7) . Hall and Elliman (2006) **Health for all Children**. OUP Oxford; New ed of 4 Revised ed edition.
- (8) O'Reilly, Sakkalou, Sakki, Dale N, Salt, Dale N J (2014) **Behaviour** difficulties in the early years of children with profound or severe visual

impairment. The Royal College of Ophthalmology Congress, Birmingham, May 2014

- (9) Sakkalou, O'Reilly, Sakki, de Haan, Salt, Dale (2013) **Early brain and social development in infants with severe visual impairment at risk of autism**. Annual Scientific Meeting of the British Autism Study of Infant Siblings, Birkbeck College, London, October 2013.
- (10). Dale and Sonksen (2002) 'Developmental outcome, including setback, in young children with severe visual impairment' **Developmental Medicine** and Child Neurology 2002, 44: 613-622
- (11). Perez-Pereira and Comti-Ramsden (1999) Language Development and Social Interaction in Blind Children Psychology Press, Sussex