

FTD 06

Ymateb gan: Cŵn Tywys Cymru Response from: Guide Dogs Cymru

Guide Dogs Cymru welcomes the decision by the Committee to consider the extent to which Welsh Government policies and programmes support the early parent role, before birth and during the first 2 years of a child's life, and crucially how effective these are in supporting children's emotional and social capabilities and development.

The Committee will be aware that there are around 2000 blind and partially sighted children and young people in Wales. These children need extra support throughout their lives and especially during the first 2 years after they are born.

Particularly important to children in their first two years of life is access to habilitation (mobility and life skills) training. Parents also need help and support including early diagnosis and emotional support. This need is recognised by the Welsh Government in the Codes of Practice supporting the Social Services and Well-Being (Wales) Act. The Part 2 Code of Practice states:

"185. Habilitation is central in enabling children and adults with a disability to live as independently as possible with the right level of support as it is key to acquiring and developing skills that otherwise would have been learnt incidentally. It is vital where an individual has been unable or delayed in developing those skills. Identifying preventative services that help people to learn, keep or improve skills and functional ability is integral to promoting well-being. As with reablement, effective habilitation should support physical, sensory, social and emotional needs and be delivered in partnership between the local authority and the Local Health Board. Habilitation support may differ from standard reablement services and require a different approach, one that focuses on the specific needs of the individual and their family. As a result, a more structured programme of support may be required, and for a longer period of time".

Clearly if local authorities in Wales follow this Code they will be tackling child health inequalities for children who are blind or partially sighted. They will certainly help to achieve the goal of supporting effective child development and emotional and social well-being. To be most effective habilitation should be provided from birth (or as soon as possible after sight loss) when prompt referral from health professionals into habilitation is essential. If children are not referred at a very early stage their parents are not enabled to provide the best support for them. Research shows children with visual impairment perform less well than other children on various measures. In fact, they were judged to have substantially poorer health-related quality of life than children with other chronic health conditions such as epilepsy, cerebral palsy and cystic fibrosis.

Guide Dogs Cymru recently carried out research with all the local authorities in Wales. The 2016 survey was a full census of the 22 local authorities in Wales and an exceptional response rate of 100 per cent was achieved. Copies of the report in English and Welsh are available from Adrian.linney@guidedogs.org.uk.

The main findings of the research were:

- There is a concern that Local Authorities are not properly identifying all CYP who have a visual impairment, when comparing their reported data, with Office for National Statistics, ONS, prevalence data;
- Across the whole of Wales there are only 8.6 FTE children's habilitation specialists with 10 Local Authorities not employing any. We estimate the number employed, directly or indirectly, should be between 15 –19 FTE to meet need.
- The number of specialist teachers of the visually impaired has declined by 12 per cent since 2012 whilst the caseload of children has shown a small increase.
- Specialist social workers (visual impairment) have virtually disappeared in Wales with only 3.2 FTE remaining and these are primarily assigned to adult teams.
- The vast majority of rehabilitation officers who support children work primarily in adult services.
- Only 55 per cent of Local Authorities use the National Sensory Impairment Partnership, NatSIP, quality framework for determining eligibility for services. Only the Gwent and Cardiff services report involving parents and children in the decision making process.

- A person-centred approach involving the CYP should be at the heart of decision-making of all local authorities.
- Fifty per cent of Local Authorities provide no service or a reduced service in school holiday time.
- The data collection work demonstrated that there was often a disconnect between education and social services with regard to co-operation and co-ordination of habilitation services.
- Overall levels of service do not appear to match the expectations of the Social Services and Well-being (Wales) Act Codes of Practice in terms of children's habilitation service.

These findings confirm that a lot more needs to be done to help blind and partially children in the first 1000 days of their lives. The Welsh Government needs to be held to account for the lack of service for these children. A good starting point would be for the Committee to ask the Welsh Government how the following could be delivered:

1. Local authorities to raise the importance of habilitation services for children and young people with a visual impairment, and be reminded of their responsibilities in relation to Social Services and Well-being (Wales) Act.
2. For joined up working between health, education and social services teams to ensure a prompt and effective referral pathway to habilitation services.
3. For all local authorities to have access to at least one full time habilitation specialist.
4. For all local authorities to use the NatSIP Eligibility Criteria for Scoring Support Levels when delivering services to children and young people with a visual impairment and their families.

Guide Dogs Cymru does help with these issues. We employ habilitation specialists across Wales and some local authorities spot purchase our services. However, we are a charity and our services are funded by public donations. We are not in a position to prop up failing public services. We would suggest the Committee seeks assurances and timeframes from the Welsh Government about what it is going to do to provide proper support for very young blind and partially sighted children in Wales.