

Exploring the training needs of health visitors working with children with Down syndrome: A pilot study

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Study 1: Down syndrome training for health visitors

We aimed to explore health visitors' existing knowledge of Down syndrome (DS), investigate health visitors' information and training needs about health care in DS and develop and evaluate a pilot DS training session for health visitors.

Twenty-six health visitors from two NHS Trusts took part in one of five group training workshops. The training lasted 45-60 minutes, and outlined the key health issues for babies and young children with DS, how these are monitored and where to find more information.

Before and after the training, health visitors completed two questionnaires about their understanding of 12 different health domains in DS (e.g. cardiac problems, physical development) and specific aspects of knowledge about DS (e.g. What blood tests should be done routinely for children with Down syndrome?). After the training, health visitors provided feedback on the training session.

Seventeen (65%) health visitors had children with DS on their caseload currently and/or in the past. Two health visitors had received training about DS previously when they were nurses. Sixteen (62%) had received information about DS previously from sources including websites (e.g. DS charities, NHS choices), through special needs health visiting colleagues and DS resources.

Before the training, on average, health visitors rated their understanding of health issues in DS as limited and their scores on the specific knowledge questions was low. The training significantly increased scores on both questionnaires, indicating improvements in taught knowledge and a more general confidence in their understanding of a range of health issues in DS.

Health visitors rated the training very highly but made some suggestions for the future e.g. allowing more time for discussion, involving parents, including case studies and providing information about local services. Health visitors stated that half-day and full-day training courses, conferences and e-learning would be the best ways of finding out more about DS.

Study 2: Parents' experiences of health visiting for children with DS

We aimed to survey parents/carers of young children with DS to find out their views of health visiting services. Parents/carers of children with DS aged 0-5 years attending a DS support group were asked to complete a short questionnaire about their experience of health visiting support over the previous 12 months.

Twenty-four parents/carers completed the questionnaire. 13 (54%) parents knew who their health visitor was. Over the previous 12 months, the average number of visits from the health visitor was 1.25 (range 0-5). The most common activity at a visit was the child being weighed (reported by 9 parents/carers). Eight parents/carers felt that they needed additional support from their health visitor, particularly to provide advice about best to support their child (e.g. feeding and toileting) and local services available.

Conclusions

This is the first study which has explored the training and support needs of health visitors regarding DS. Health visitors and parents/carers would welcome further training for health visitors to improve their knowledge and understanding about health and development in DS and how best to support this. Further research with a larger sample of health visitors is needed, and the effects of health visitor training on children's and families' outcomes needs to be evaluated.

Acknowledgements

We'd like to thank all health visitors and parents who took part in this study, and the health visiting and research managers at Hertfordshire Community NHS Trust and Central London Community NHS Trust. We gratefully acknowledge the funding provided by Baily Thomas Charitable Fund (TRUST/VC/AC/SG/3718/6500). The views in this report represent those of the authors, not the funding body.

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