Journal of Policy and Practice in Intellectual Disabilities

Journal of Policy and Practice in Intellectual Disabilities doi: 10.1111/jppi.12271

Evaluating Health Visitors' Existing Knowledge of Down Syndrome and the Effect of a Training Workshop

Silvana E. Mengoni* , and Sandra Redman†

*Department of Psychology and Sports Sciences, Centre for Health Services and Clinical Research, University of Hertfordshire, UK; and †Talking Downs, Stevenage, UK

Abstract

Children with Down syndrome are at an increased risk of health and development issues in early childhood, therefore monitoring their development and identifying health conditions as early as possible is critical. Health professionals may not always have the training and knowledge to effectively support families of children with disabilities, including Down syndrome. In the UK, health visitors conduct health and development reviews for children under 5 years, therefore they have a key role to play in monitoring and identifying health issues in young children with Down syndrome. However there has been no research on health visitors' knowledge and training needs regarding Down syndrome. This study aimed to assess health visitors' existing knowledge of Down syndrome and evaluate a pilot Down syndrome training session for health visitors. Twenty-six health visitors from two NHS Trusts in England participated in 1 of 5 group training workshops. Pretraining and posttraining questionnaires assessed knowledge about Down syndrome, and feedback on the training session. Knowledge about Down syndrome was low prior to the training and increased significantly following the training session. Health visitors rated the training workshop very highly and would recommend it to a colleague. Health visitors identified a need for training to enable them to increase their knowledge about Down syndrome and better support families. In summary, a pilot training session about Down syndrome received positive feedback from health visitors, and led to improvements in knowledge and understanding about Down syndrome. This has the potential to improve health outcomes for children with Down syndrome.

Keywords: down syndrome, early development, health visiting, intellectual disabilities, workforce development

Introduction

Down syndrome is the most common genetic cause of intellectual disability, typically caused by the presence of an extra chromosome 21. In the UK, 700–800 babies with Down syndrome are born each year (Wu & Morris, 2013), with a prevalence of 9.11 per 10,000 in children aged under 5 years (Alexander et al., 2016).

People with Down syndrome are at a higher risk of multiple health problems than the general population throughout their lifespan (Pikora et al., 2014; Schieve, Boulet, Boyle, Rasmussen, & Schendel, 2009; Tenenbaum, Chavkin, Wexler, Korem, & Merrick, 2012). Health issues are heightened in early childhood for children with Down syndrome, with high levels of support and therapy needed (Geelhoed, Bebbington, Bower, Deshpande, & Leonard, 2011; Marshall, Tanner, Kozyr, & Kirby, 2015; Schieve et al., 2009; Schieve, Boulet, Kogan, Van Naarden-Braun, & Boyle, 2011). Common health problems for babies and children with Down syndrome include heart defects, respiratory conditions, bowel conditions, musculoskeletal problems, hearing problems, visual impairments, and allergies (Cleves et al., 2007; Frid, Annerén, Rasmussen, Sundelin, & Drott, 2002; McGrath, Stransky, Cooley, & Moeschler, 2011; Schieve et al., 2009; Thomas et al., 2011).

The impact of such health issues on health services utilisation is high, for example, Schieve et al. (2009) found that over 25% of children with Down syndrome needed help with personal care, took regular medication, had recently seen a medical specialist and had received therapy. An increased likelihood of health problems and unmet health needs also have an impact on family life, including financial problems and parental unemployment (McGrath et al., 2011; Phelps, Pinter, Lollar, Medlen, & Bethell, 2012).

Health professionals are often reported to have a poor understanding of intellectual disability and associated health problems (Melville et al., 2005; Michael, 2008; Special Olympics, 2005). A systematic review identified training needs amongst health professionals working in mainstream services about intellectual disabilities in general, and regarding health problems

Received October 10, 2017; accepted May 17, 2018
Correspondence: Silvana E. Mengoni, Centre for Health Services and Clinical Research, Department of Psychology and Sports Sciences, University of Hertfordshire, AL10 9AB, UK. Tel: 01707 284494; E-mail: s.mengoni@herts.ac.uk

that may be more prevalent in people with intellectual disabilities (Hemm, Dagnan, & Meyer, 2015).

Considering screening and diagnosis of Down syndrome, there have been calls for more comprehensive information and support to be provided to parents and for more training for health professionals (Muggli, Collins, & Marraffa, 2009; Sheets, Best, Brasington, & Will, 2011; Skotko, Capone, & Kishnani, 2009; Williams, Alderson, & Farsides, 2002). However, there is comparatively little research about experiences and support needed in early childhood. Minnes and Steiner (2009) found that parents of children and adults with Down syndrome felt that health professionals sometimes displayed a lack of knowledge about Down syndrome and attributed health symptoms to their child having Down syndrome rather than a separate and treatable health problem. Attributing health problems to the intellectual disability rather than recognising and addressing them as a co-morbid issue is known as "diagnostic overshadowing" (Reiss, Levitan, & Szyszko, 1982), and may indicate a lack of knowledge and a need for training.

Health surveillance guidelines for Down syndrome have been published, which aim to improve early identification and support for health issues, thereby improving long-term outcomes for people with Down syndrome (Baum et al., 2008; Bull & The Committee on Genetics, 2011; Charleton, Dennis, & Marder, 2010; Van Cleve & Cohen, 2006). The Down Syndrome Medical Interest Group (DSMIG) have published such guidelines and advice as an insert for the Personal Child Health Record (PCHR or "red book") (DSMIG, 2011), which is a UK health and development record given to all parents at a child's birth. However a small but growing body of research suggests that such health surveillance guidelines are not consistently followed by healthcare professionals, although there is limited research in the UK (Santoro, Yin, & Hopkin, 2017; Skotko, Davidson, & Weintraub, 2013; Virji-Babul, Eichmann, Kisly, Down, & Haslam, 2007).

Children with Down syndrome may be in contact with many professionals in the early years, who are involved in their healthcare. In the UK, a key group of health professionals in the early years are health visitors, as they work with, and support all families during the early years of a child's life. Health visitors are qualified nurses or midwives who have undertaken a further training course to become a health visitor. As part of their role, health visitors conduct five key visits between pregnancy and age 2.5 years. At these visits, health visitors offer advice and support to families and review the child's health and development. These five heath reviews are an universal service, but for children with disabilities and long-term conditions, health visitors are expected to provide additional support to families (Public Health England, 2018).

As the early years are such a critical time for monitoring health, identifying issues and implementing support and interventions, health visitors may play a particularly important role in ensuring the healthy development of children with Down syndrome. In a parental survey, approximately a third of parents of children with Down syndrome reported that they needed additional support from health visitors (Mengoni & Redman, in press). Therefore, it is important to understand the level of health visitors' knowledge about Down syndrome and what training needs they may have.

Aims

Monitoring and supporting the health needs of children with Down syndrome is critical in the early years. The role of health visitors is particularly important for families of children with Down syndrome, but no studies have examined the knowledge and training needs of this group. This study aimed to:

1. Assess health visitors' existing knowledge of Down syndrome.
2. Evaluate a pilot Down syndrome training package.

Methods

Design

A repeated-measures design was used. All participating health visitors took part in a training workshop, and completed pretraining and posttraining questionnaires to assess their knowledge of Down syndrome and satisfaction with the training workshop.

In the Kirkpatrick Model of training evaluations, there are four levels of evaluation: reaction, learning, behaviour, and results (Kirkpatrick & Kirkpatrick, 2006). This training study was designed to focus on the first two levels: reaction, that is, trainee's opinions of the training, and learning, that is, the degree to which knowledge is increased.

Ethical approval was obtained from the University of Hertfordshire and permission was obtained from the NHS Trusts involved, following Health Research Authority (HRA) procedures. Informed consent was provided by all participants.

Participants

Two NHS Trusts in England agreed to take part in the study and distributed information about the study to their health visitors, including times and locations of the workshops. All health visitors were eligible to take part, regardless of whether they had worked with children with Down syndrome before or not.

Twenty-six health visitors from the two NHS Trusts took part in the study. All participants were female. The mean length of time they had spent in a health visiting role was 7.09 years (standard deviation = 10.29) and ranged from 0 to 39 years, which included one student health visitor.

Down Syndrome Training

The training programme was based on existing research and best practice, including health surveillance information from the DSMIG and health information available from Down Syndrome Association. General information about Down syndrome was presented, including cause and prevalence. After an overview of common health issues, the following topics were discussed in detail: blood disorders, cardiac problems, thyroid disorders, feeding difficulties, gastrointestinal problems, visual difficulties, diabetes, cervical spine abnormalities, sleep, hearing, epileptic spasms, and oral health. Attendees were signposted to relevant websites and informed about Down syndrome resources for monitoring development.

The training was led by an experienced trainer (second author) using PowerPoint slides, handouts, and an interactive format. The training presentation lasted approximately 45–60 min. The workshops took place on University and NHS premises, depending on the NHS Trust's preference. Five training workshops took place in total between October 2015 and April 2016, and the number of attendees at each workshop ranged from 2 to 12.

Questionnaires

Background Questionnaire. Health visitors completed questions about their role, their experiences working with children with Down syndrome, and training and access to information about Down syndrome. This questionnaire was administered prior to the training.

Down Syndrome Knowledge. There were two questionnaires to assess knowledge of Down syndrome (Table 1).

One questionnaire was devised to test whether the training was successful in teaching specific key facts about health issues in Down syndrome ("proximal knowledge questionnaire"). This questionnaire consisted of seven questions which reflected key health issues that were covered in the training, and was administered before and after the training. A mark scheme was produced prior to administering the questionnaire, and all questionnaires were double-marked with any disagreements arbitrated by a third marker.

A second questionnaire was designed to measure health visitor's self-rated knowledge of broad areas of health and development in children with Down syndrome ("distal knowledge questionnaire"). Health visitors were asked to rate their knowledge about 12 key health issues (e.g., vision and cardiac abnormalities) in Down syndrome on a scale from 0 to 3. This was administered before and after the training.

Feedback Questionnaire. An important aspect of a training evaluation is whether it would be successfully received in practice. Therefore after the training, health visitors were asked to rate eight aspects of the training to indicate their satisfaction with the workshop (see Table 1 for more detail). They were also asked to indicate their three preferred formats for Down syndrome training. The formats included full-day training, half-day training, e-learning, talks by external speakers, books, and peer support. Free-text comments about the training session were also invited.

TABLE 1
Bespoke questionnaire design

	Proximal knowledge questionnaire	Distal knowledge questionnaire	Feedback questionnaire
Aim	Assess proximal outcomes via specific questions about content in the training session	Assess distal outcomes via questions about extent of knowledge in 12 broad areas of health and development	Gather health visitors' views on training
Content	There were seven question, for example,: • What is the prevalence of Down syndrome? • What blood tests should be done routinely for children with Down syndrome? • What eye conditions are common in Down syndrome?	12 key topics were covered: • Blood disorders • Cardiac abnormalities • Cervical spine • Cognitive development • Dental problems • Feeding • Gastrointestinal problems • Hearing • Respiratory problems • Physical development • Thyroid problems • Vision	Participants were asked to indicate their agreement with eight statements about the training: • Content • Level of detail • Interest • Length • Impact on job • Likelihood of using resources • Effectiveness of instructor • Whether they would recommend the training to colleagues. Free-text comments were also invited. They were also asked about preferred formats for training.
Scoring scheme	A bespoke marking scheme was used, and questionnaires were double-scored. Maximum score of 24.	A scale of zero to three was used for each domain: 0 = no knowledge 1 = limited knowledge 2 = some knowledge 3 = good knowledge. Maximum score of 36.	Feedback rating - scoring scale from 1 (strongly disagree) to 5 (strongly agree) for each question.

Data Analysis

Data about the health visitors' background and training feedback were tabulated and means were reported to inform the evaluation of the training. Pretraining and posttraining scores on the knowledge questionnaires were compared using paired *t*-tests on SPSS 22 (IBM Corp, 2013).

Results

Experience Regarding Down Syndrome

Fifteen of the 26 health visitors (58%) currently had children with Down syndrome on their caseload, and an additional two health visitors had previously had children with Down syndrome on their caseload. Fourteen of these health visitors, along with two health visitors who had not worked with children with Down syndrome had accessed information about Down syndrome from sources including health and condition-specific websites (e.g., NHS Choices and Down's Syndrome Association), discussions with specialist health visitors and specific Down syndrome resources. Two health visitors (8%) indicated that they were aware of health surveillance charts such as the PCHR Down syndrome insert. Only two health visitors had received training about Down syndrome, and for both, this had been during nursing training, that is, prior to becoming a health visitor. In total, five health visitors (19%) had never had a child with Down syndrome on their caseload, had never accessed information about Down syndrome and had never received training about Down syndrome.

Knowledge of Down Syndrome

In order to assess existing knowledge of Down syndrome and evaluate how well the training workshop improved knowledge, the mean scores on the pretraining and posttraining knowledge questionnaires were examined and compared. The mean scores and standard deviations are shown in Table 2.

The proximal knowledge questionnaire was designed to target topics presented in the training, and the pretraining scores were very low. There was a significant difference between pretraining (M = 4.31, SD = 1.59) and posttraining scores (M = 12.19, SD = 2.53), as shown by a paired t-test, $t(25) = -13.236$, $p < .001$.

The distal knowledge questionnaire assessed broader knowledge about domains of health and development in Down syndrome. One health visitor omitted all posttraining distal knowledge questions, and one health visitor omitted the pretraining knowledge question about blood disorders.

There was a significant difference between the pretraining distal knowledge total score (M = 12.08, DS = 6.52) and the posttraining total score (M = 27.08, SD = 4.73); $t(24) = -14.389$, $p < .001$.

Examination of the pretraining mean score per question indicated a limited knowledge of health issues in Down syndrome. Health visitors rated their understanding of cervical spine abnormalities (mean = 0.32) as the lowest and cognitive development (mean = 1.52) as the highest (Table 3). After training, the scores on each question were very similar (Table 3). As with the pretraining scores, the lowest score was cervical spine abnormalities (mean = 2.14) and the highest was cognitive development (mean = 2.34). As tested by paired t-tests, improvements on all questions were highly significant ($p < .001$ for all comparisons; see Table 3).

TABLE 2
Scores on the knowledge questionnaires

	Proximal knowledge	Distal knowledge[1]
Pretraining mean (standard deviation)	4.31 (1.59)	12.08 (6.52)
Posttraining mean (standard deviation)	12.19 (2.53)	27.08 (4.73)
Maximum possible score	24	36

[1] n = 25 due to missing data from one health visitor at the posttraining questionnaire.

Training Feedback

The training was rated very highly with all participants "strongly agreeing" (i.e., giving the maximum score of 5) with statements about relevance of training, level of detail, likely impact on job, likelihood of using the signposted resources, effectiveness of the instructor, and whether they would recommend the training to colleagues. The questions about the length of the session (mean = 4.52) and whether the material was presented in an interesting way (mean = 4.90) were also rated very highly.

Health visitors were asked to indicate their preferred formats of future training or education about Down syndrome. The most popular options were half-day and full-day training courses, conferences or talks and e-learning, which were all chosen by approximately half of the health visitors.

In the free-text comments, the majority of health visitors highlighted the value of the training session, and suggestions were made to roll out the training to all health visitors, GPs and school nurses. Suggestions to improve the training included:

- Parent representation at the training
- More time for discussion
- Group work around health visitor's experiences and example cases
- Information about local procedures and support.

Discussion

This study aimed to explore health visitors' existing knowledge of Down syndrome, and evaluate a pilot Down syndrome

TABLE 3
Scores on the distal knowledge questionnaire for each domain of health and development

	Pretraining mean score (standard deviation)	Posttraining mean score (standard deviation)	*t*-test for difference between pretraining and posttraining scores
Blood disorders	0.42 (0.72)	2.23 (0.42)	$t(23) = -12.09, p < .001$
Cardiac abnormalities	1.28 (0.61)	2.26 (0.44)	$t(24) = -7.90, p < .001$
Cervical spine	0.32 (0.56)	2.14 (0.60)	$t(24) = -14.51, p < .001$
Cognitive development	1.52 (0.71)	2.34 (0.47)	$t(24) = -5.94, p < .001$
Dental problems	0.92 (0.76)	2.30 (0.46)	$t(24) = -10.36, p < .001$
Feeding	1.48 (0.71)	2.30 (0.46)	$t(24) = -5.11, p < .001$
Gastrointestinal problems	1.04 (0.89)	2.22 (0.41)	$t(24) = -6.92, p < .001$
Hearing	0.92 (0.95)	2.30 (0.46)	$t(24) = -8.84, p < .001$
Respiratory problems	1.08 (0.76)	2.22 (0.41)	$t(24) = -7.82, p < .001$
Physical development	1.44 (0.65)	2.26 (0.44)	$t(24) = -5.94, p < .001$
Thyroid problems	0.72 (0.84)	2.26 (0.44)	$t(24) = -10.10, p < .001$
Vision	0.96 (0.84)	2.26 (0.44)	$t(24) = -9.19, p < .001$

NB mean scores are shown pairwise, that is, only scores from health visitors who answered both the pretraining and posttraining question have been included.

training package. The findings indicated that health visitors had low levels of existing knowledge of Down syndrome. A short training workshop significantly increased knowledge about Down syndrome, and received positive feedback from health visitors.

Healthcare needs can be high for people with Down syndrome in their early years (Dawson et al., 2014; Geelhoed et al., 2011). Therefore it is important that health services are meeting the needs of young children with Down syndrome and their families by identifying and addressing potential health issues. As a universal service in the UK for children aged 0–5 years, health visiting should be well-placed to contribute to these aims, and improve long-term outcomes for children and families. However these findings suggest that health visitors may have limited knowledge about common health and development issues in Down syndrome due to a lack of training, and that they recognized this training need. This mirrors results from Halpin and Nugent (2007), who found that health visitors felt that their prior training was not adequate to help them identify children with autism spectrum disorder. A lack of understanding about developmental disorders such as Down syndrome in healthcare professionals is important, as this may lead to diagnostic overshadowing (Minnes & Steiner, 2009), hindering appropriate and timely intervention.

The short training workshop in this study led to immediate improvements in health visitors' knowledge about taught topics and broader health and development issues in Down syndrome. A feedback questionnaire indicated that health visitors valued the training, and indicated a desire for further in-depth training. Full-day training regarding screening and diagnosis for Down syndrome developed by Down Syndrome Association (2016) has been found to improve midwives' knowledge of Down syndrome and confidence in communication about Down syndrome, with some evidence of behavior change in clinical practice (Bryant, Puri, Dix, & Ahmed, 2016). However, as highlighted by Bryant et al. (2016), such training needs to be incorporated into mandatory professional education, that is, Specialist Community Public Health Nursing.

Health surveillance guidelines are recommended for use with people with Down syndrome, and are available in the UK. However, only two health visitors (8%) in the study indicated that they were aware of such guidelines. Along with the overall findings of low levels of knowledge about Down syndrome, this suggests that effective health surveillance may not be carried out by all health visitors. However it may be that other professionals are fulfilling this role, for example, pediatricians, and further research is needed to establish the extent to which health surveillance is being conducted according to guidelines.

Limitations

Two neighboring NHS Trusts took part in the training workshop, so findings cannot be generalized across the UK. As this was a small-scale study, the sample size was relatively small and bespoke unvalidated questionnaires were used. Furthermore, the sample was self-selecting and may not be representative.

Health visiting has undergone a number of changes in recent years (Peckover, 2013); a lack of resources and an emphasis on meeting organisational targets has been reported, which has the potential to lead to fewer visits and reduced support for some families (Greenway, Entwistle, & terMeulen, 2013). Furthermore, other professionals also have responsibility for the healthcare of children with Down syndrome, such as pediatricians and GPs. As such, it is important to understand the role of different services in health surveillance, and evaluate overall service delivery for children with Down syndrome.

It is encouraging that a short training workshop improved health visitors' knowledge but health visitors expressed a preference for a longer training session, and the inclusion of parent views and group discussion. If the training time was extended it would be possible to address some of the improvements suggested by health visitors, and go beyond the health profile of children with Down syndrome to include broader issues

affecting parents, insights into the experiences of other health visitors and local support infrastructure. Service user involvement would also be important to include, involving parents and children and young people with Down syndrome in the design and delivery of the training. However the practicalities and cost of rolling out such training nationally would need consideration.

It was not possible to assess changes in routine clinical practice in this study, which is a limitation to a training evaluation study (Kirkpatrick & Kirkpatrick, 2006). In the Kirkpatrick model, one level of evaluation is "behavior." This study was not able to address this, but predicted changes in behavior may include sharing knowledge with colleagues, introducing Down syndrome resources and information to parents, and increased referrals to specialist services. Training feedback was positive and improvements in knowledge about Down syndrome were evident. These preliminary findings indicate that there is a clear basis for future research to assess longer-term clinical outcomes, such as whether training would lead to earlier identification of health issues and early support, and therefore improve long-term outcomes for children with Down syndrome and their families.

Conclusion

Children with Down syndrome are at an increased risk for health and development issues in the early years. As a universal service, health visitors are in a unique position within health services and may have the opportunity to identify developmental issues that could otherwise go unnoticed. However in order to do so, they need to be aware of common health and development issues which may co-occur with Down syndrome and what to do about these, including using existing resources, signposting to resources for parents and referral to appropriate services. The present research suggests that many health visitors may not have the knowledge to identify issues and fully support families, but this may be improved by specialist training. Therefore it is crucial that health visitors are able to access training about Down syndrome in order to identify potential issues, refer to appropriate services, and provide advice to parents and signpost to relevant resources.

Acknowledgments

The authors would like to thank the health visitors and parents who took in the study, along with Karen Afford at Hertfordshire Community NHS Trust for her support. The assistance of the health visiting services in Hertfordshire Community NHS Trust and Central London Community NHS Trust, and Downright Excellent in facilitating recruitment is gratefully acknowledged. The authors also thank Fiona Pearce for her help with data scoring and literature searching.

Conflict of interest

SR conducts training for professionals about Down syndrome, but has received no financial gain related to this project (other than payment for time spent directly on the project).

Source of funding

This research was funded by Baily Thomas Charitable Fund and was independently conducted (ref no: TRUST/VC/AC/SG/3718/6500).

References

Alexander, M., Ding, Y., Foskett, N., Petri, H., Wandel, C., & Khwaja, O. (2016). Population prevalence of Down's syndrome in the United Kingdom. *Journal of Intellectual Disability Research*, *60*, 874–878. doi:https://doi.org/10.1111/jir.12277.

Baum, R. A., Nash, P. L., Foster, J. E. A., Spader, M., Ratliff-Schaub, K., & Coury, D. L. (2008). Primary care of children and adolescents with down syndrome: An update. *Current Problems in Pediatric and Adolescent Health Care*, *38*, 241–261. doi:https://doi.org/10.1016/j.cppeds.2008.07.001.

Bryant, L. D., Puri, S. C., Dix, L., & Ahmed, S. (2016). Tell it Right, Start it Right: An evaluation of training for health professionals about Down syndrome. *British Journal of Midwifery*, *24*, 110–117. doi:https://doi.org/10.12968/bjom.2016.24.2.110.

Bull, M. J., & The Committee on Genetics. (2011). Clinical report—Health supervision for children with Down syndrome. *Pediatrics*, *128*, 393–406. doi:https://doi.org/10.1542/peds.2011-1605.

Charleton, P. M., Dennis, J., & Marder, E. (2010). Medical management of children with Down syndrome. *Paediatrics and Child Health*, *20*, 331–337. doi:https://doi.org/10.1016/j.paed.2010.06.006.

Cleves, M. A., Hobbs, C. A., Cleves, P. A., Tilford, J. M., Bird, T. M., & Robbins, J. M. (2007). Congenital defects among liveborn infants with Down syndrome. *Birth Defects Research Part A: Clinical and Molecular Teratology*, *79*, 657–663. doi:https://doi.org/10.1002/bdra.20393.

Down Syndrome Association. (2016). *About Down's syndrome: Tell It Right Start It Right*. Retrieved from http://www.downs-syndrome.org.uk/about/training/tell-it-right/

Dawson, A. L., Cassell, C. H., Oster, M. E., Olney, R. S., Tanner, J. P., Kirby, R. S., … Grosse, S. D. (2014). Hospitalizations and associated costs in a population-based study of children with Down Syndrome born in Florida. *Birth Defects Research Part A: Clinical and Molecular Teratology*, *100*(11), 826–836.

DSMIG. (2011). *PCHR insert* Retrieved from www.dsmig.org.uk/publications/pchr.html.

Frid, C., Annerén, G., Rasmussen, F., Sundelin, C., & Drott, P. (2002). Utilization of medical care among children with Down's syndrome. *Journal of Intellectual Disability Research, 46*, 310–317. doi:https://doi.org/10.1046/j.1365-2788.2002.00392.x.

Geelhoed, E. A., Bebbington, A., Bower, C., Deshpande, A., & Leonard, H. (2011). Direct health care costs of children and adolescents with Down syndrome. *Journal of Pediatrics, 159*, 541–545. doi:https://doi.org/10.1016/j.jpeds.2011.06.007.

Greenway, J. C., Entwistle, V. A., & terMeulen, R. (2013). Ethical tensions associated with the promotion of public health policy in health visiting: A qualitative investigation of health visitors' views.

Primary Health Care Research & Development, *14*, 200–211. doi: https://doi.org/10.1017/S1463423612000400.

Halpin, J., & Nugent, B. (2007). Health visitors' perceptions of their role in autism spectrum disorder. *Community Practitioner, 80*, 18–22.

Hemm, C., Dagnan, D., & Meyer, T. D. (2015). Identifying training needs for mainstream healthcare professionals, to prepare them for working with individuals with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, *28*, 98–110. doi:https://doi.org/10.1111/jar.12117.

IBM Corp. (2013). *IBM SPSS statistics for windows, version 22.0*. Armonk, NY: IBM Corp.

Kirkpatrick, D. L., & Kirkpatrick, J. D. (2006). *Evaluating training programs: The four levels* (3rd). San Francisco: Berett-Koehler Publishers, Inc.

Marshall, J., Tanner, J. P., Kozyr, Y. A., & Kirby, R. S. (2015). Services and supports for young children with Down syndrome: Parent and provider perspectives. *Child: Care, Health & Development*, *41*, 365–373. doi:https://doi.org/10.1111/cch.12162.

McGrath, R. J., Stransky, M. L., Cooley, W. C., & Moeschler, J. B. (2011). National profile of children with Down syndrome: Disease burden, access to care, and family impact. *The Journal of Pediatrics*, *159*, 535.e2–540.e2. doi:https://doi.org/10.1016/j.jpeds.2011.04.019.

Melville, C. A., Finlayson, J., Cooper, S. A., Allan, L., Robinson, N., Burns, E., … Morrison, J. (2005). Enhancing primary health care services for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *49*, 190–198. doi:https://doi.org/10.1111/j.1365-2788.2005.00640.x.

Mengoni, S. E., & Redman, S. (in press). Parents' experiences of health visiting for children with Down syndrome. Journal of Health Visiting.

Michael, J. (2008). *Healthcare for all: Report of the independent inquiry into access to healthcare for people with learning disabilities*. Retrieved from http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255.

Minnes, P., & Steiner, K. (2009). Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome. *Child: Care, Health and Development, 35*, 250–256. doi:https://doi.org/10.1111/j.1365-2214.2008.00931.x.

Muggli, E. E., Collins, V. R., & Marraffa, C. (2009). Going down a different road: First support and information needs of families with a baby with Down syndrome. *Medical Journal of Australia, 190*, 58–61.

Peckover, S. (2013). From 'public health' to 'safeguarding children': British health visiting in policy, practice and research. *Children & Society*, *27*, 116–126. doi:https://doi.org/10.1111/j.1099-0860.2011.00370.x.

Phelps, R. A., Pinter, J. D., Lollar, D. J., Medlen, J. G., & Bethell, C. D. (2012). Health care needs of children with Down syndrome and impact of health system performance on children and their families. *Journal of Developmental & Behavioral Pediatrics*, *33*, 214–220. doi: https://doi.org/10.1097/DBP.0b013e3182452dd8.

Pikora, T. J., Bourke, J., Bathgate, K., Foley, K.-R., Lennox, N., & Leonard, H. (2014). Health conditions and their impact among adolescents and young adults with Down syndrome. *PLoS One*, *9*, e96868. doi:https://doi.org/10.1371/journal.pone.0096868.

Public Health England. (2018). *Best start in life and beyond: Improving public health outcomes for children, young people and families: Commissioning guide 2*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/686930/best_start_in_life_and_beyond_commissioning_guidance_2.pdf

Reiss, S., Levitan, G. W., & Szyszko, J. (1982). Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency, 86*, 567–574.

Santoro, S. L., Yin, H., & Hopkin, R. J. (2017). Adherence to symptom-based care guidelines for down syndrome. *Clinical Pediatrics, 56*, 150–156. doi: https://doi.org/10.1177/0009922816652416.

Schieve, L. A., Boulet, S. L., Boyle, C., Rasmussen, S. A., & Schendel, D. (2009). Health of children 3 to 17 years of age with Down syndrome in the 1997–2005 National Health Interview Survey. *Pediatrics*, *123*, e253–e260. doi:https://doi.org/10.1542/peds.2008-1440.

Schieve, L. A., Boulet, S. L., Kogan, M. D., Van Naarden-Braun, K., & Boyle, C. A. (2011). A population-based assessment of the health, functional status, and consequent family impact among children with Down syndrome. *Disability and Health Journal*, *4*, 68–77. doi: https://doi.org/10.1016/j.dhjo.2010.06.001.

Sheets, K. B., Best, R. G., Brasington, C. K., & Will, M. C. (2011). Balanced information about Down syndrome: What is essential? *American Journal of Medical Genetics, Part A, 155*, 1246–1257. doi: https://doi.org/10.1002/ajmg.a.34018.

Skotko, B. G., Capone, G. T., & Kishnani, P. S. (2009). Postnatal diagnosis of Down syndrome: Synthesis of the evidence on how best to deliver the news. *Pediatrics*, *124*, e751–e758. doi:https://doi.org/10.1542/peds.2009-0480.

Skotko, B. G., Davidson, E. J., & Weintraub, G. S. (2013). Contributions of a specialty clinic for children and adolescents with Down syndrome. *American Journal of Medical Genetics, Part A*, *161*, 430–437. doi:https://doi.org/10.1002/ajmg.a.35795.

Special Olympics. (2005). *Changing attitudes changing the World: The health and health care of people with intellectual disabilities*. Retrieved from www.specialolympics.org/Sections/What_We_Do/Leading_Research_Studies.aspx

Tenenbaum, A., Chavkin, M., Wexler, I. D., Korem, M., & Merrick, J. (2012). Morbidity and hospitalizations of adults with Down syndrome. *Research in Developmental Disabilities, 33*, 435–441.

Thomas, K., Bourke, J., Girdler, S., Bebbington, A., Jacoby, P., & Leonard, H. (2011). Variation over time in medical conditions and health service utilization of children with Down syndrome. *The Journal of Pediatrics*, *158*, 194.e1–200.e1. doi:https://doi.org/10.1016/j.jpeds.2010.08.045.

Van Cleve, S. N., & Cohen, W. I. (2006). Part I: Clinical practice guidelines for children with Down syndrome from birth to 12 years. *Journal of Pediatric Health Care*, *20*, 47–54. doi:https://doi.org/10.1016/j.pedhc.2005.10.004.

Virji-Babul, N., Eichmann, A., Kisly, D., Down, J., & Haslam, R. H. (2007). Use of health care guidelines in patients with Down syndrome by family physicians across Canada. *Paediatrics & Child Health, 12*, 179–183.

Williams, C., Alderson, P., & Farsides, B. (2002). What constitutes 'balanced information in the practitioners' portrayals of Down's syndrome? *Midwifery*, *18*, 230–237. doi:https://doi.org/10.1054/midw.2002.0316.

Wu, J., & Morris, J. K. (2013). Trends in maternal age distribution and the live birth prevalence of Down's syndrome in England and Wales: 1938-2010. *European Journal of Human Genetics*, *21*, 943–947. doi:https://doi.org/10.1038/ejhg.2012.288.