

Parents' experiences of health visiting for children with Down syndrome

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Key words

- Intellectual disability
- Down syndrome
- Child health
- Nursing

Introduction

The prevalence of Down syndrome has been estimated at 0.66 per 1000 people in England and Wales (Wu and Morris, 2013). People with Down syndrome are at higher risk of multiple health problems than the general population for conditions including congenital heart abnormalities, hearing problems, thyroid problems and respiratory issues, with many of these health conditions beginning in early childhood (Bull and The Committee on Genetics, 2011, Thomas et al., 2011, Schieve et al., 2009, Cleves et al., 2007).

Due to the increased prevalence of health issues, children with Down syndrome typically have a high utilisation of health services and early intervention is key to improve long-term child and family outcomes (Marshall et al., 2015, Dawson et al., 2014, Schieve et al., 2009). Increased health needs and poor access to services have a negative impact on the quality of life of children with Down syndrome (Murphy et al., 2017). Furthermore, compared to other children with health conditions, families of children with Down syndrome are more likely to report unmet care needs, a lack of family support services and increased work and financial impacts (McGrath et al., 2011).

The majority of previous research exploring parents' experiences of health services for children with Down syndrome has focused on the screening and diagnosis process, and parents commonly report a lack of support, sensitivity and balanced up-to-date information from healthcare professionals (Gammons et al., 2010, Sooben, 2010, Muggli et al., 2009, Skotko, 2005a, Skotko, 2005b). Parents have also reported that some health professionals lack knowledge about Down syndrome and are not able to provide the necessary information and support to families in childhood and adulthood (Marshall et al., 2015, Minnes and Steiner, 2009).

Many healthcare professionals may be involved in the care of a child with Down syndrome in early childhood, depending on their individual needs. A key group of professionals are health visitors. Health visitors are qualified nurses or midwives who have undertaken further training, and work in the community in partnership with other practitioners to provide a tiered service to all families of children aged 0-5 years (Public Health England, 2018, Local Government Association and Institute of Health Visiting, 2017, NHS England, 2014). The 'universal' offer for all families includes conducting five key visits between pregnancy and 2.5 years to offer advice and review the child's health and development. The 'universal partnership' offer incorporates expert advice and support for families who need additional input, for example about postnatal depression or feeding. Under the 'universal partnership plus' offer, health visitors work in partnership with other services to provide additional support to families of children with disabilities or long-term conditions, such as children with Down syndrome. A recent study has shown that prior to a training workshop,

health visitors had low levels of knowledge about Down syndrome (Authors, under review).

The training significantly improved knowledge and was valued by health visitors.

Research question

During early childhood, health visitors play a key role in promoting healthy development for all children. The needs of children with Down syndrome are often greater than for children without a disability, so health visiting may be a particularly important service for this population. There is limited research in this area, therefore this preliminary study aimed to understand more about parents' experiences of health visiting for children with Down syndrome.

Methods

Design

This was a questionnaire study, with a mix of multiple-choice and open-ended questions, designed to collect information about parents' experiences of health visiting services.

The study complied with the British Psychological Society Code of Human Research Ethics and all study procedures and documents were reviewed and approved by the Health and Human Sciences Ethics Committee at the (name of institution to be included after peer review).

Participants

A support group for parents of children with Down syndrome based in London agreed to take part in this study. The study was presented at two 'stay and play' sessions and all parents/carers (hereafter referred to as parents) of children with Down syndrome aged 0-5 years attending were invited to take part in the project. Twenty-four parents completed the questionnaire and their children were aged 4 months to 4 years, with a mean of 2.5 years (standard deviation 1.22).

Questionnaire

A questionnaire was designed to collect information about families' experiences of health visiting services for their child with Down syndrome in the previous 12 months. The questions were based on the authors' experiences of working with parents with children with Down syndrome and health visitors, and the published specification of the health visiting service (NHS England, 2014). The questionnaire was brief to encourage completion and consisted of a mix of free text and multiple-choice responses. There were four questions about health visiting:

- "Do you know who your health visitor is?" The forced response options were 'yes' or 'no'.
- "Approximately how many times have you seen a health visitor in the last 12 months?" This had an open response option.
- "Over the last 12 months, what has the health visitor done during their visit or as a follow-up?" The options for this question are shown in Table 1, and parents could select all responses that were relevant

- “Do you feel that you need additional support from your health visitor(s)?” There were three response options: “no – my health visitor(s) provides appropriate support”, “no – I do not receive appropriate support from my health visitor(s) but I am receiving support from other professionals” and “yes” . There was a free text section for parents to note what they felt they needed additional support with.

Procedure

Parents were approached at a support group in London before or after their ‘stay and play’ sessions in June and July 2016. They were provided with information about the study and those who consented were given a questionnaire to complete individually in a quiet place. They then returned this questionnaire to the researcher.

Analysis

Data from the questionnaires were entered into SPSS 22 and tabulated. The free text responses to the “Do you feel that you need additional support from your health visitor(s)?” question were entered into NVivo. They were coded and organised into themes, in line with thematic analysis methodology outlined by Braun and Clarke (2006). Representative quotes are included in the results section in italics.

Results

Thirteen out of twenty-four parents (54%) reported that they knew who their health visitor was. Fifteen parents (63%) had received a visit from a health visitor in the previous 12

months. Nine parents (38%) had not received a visit in the previous 12 months; eight of these parents had children aged 3 years or older.

Of those parents who had received a visit (n=15) in the previous 12 months, the median (and mode) number of visits was 1 (interquartile range: 1-3). Parents were asked what occurred at visits from a list of options, and their responses can be seen in Table 1. The most common activity at a visit was weighing the child, which was reported by nine parents, i.e. 60% of those who received a visit in the previous 12 months. Four parents (27%) reported that a referral was made to another professional as a result of the visit. In total seven parents (47%) reported that advice was provided (see Table 1 for breakdown of different types of advice).

Table 1. Activities at health visit in previous 12 months

| Activities at health visit | Number of parents (% of those receiving a visit) |
|--|--|
| Weighed the child | 9 (60%) |
| Carried out a developmental check | 4 (27%) |
| Referred the child to another professional | 4 (27%) |
| Provided advice about weaning | 3 (20%) |
| Provided advice about toileting | 3 (20%) |
| Provided advice about sleeping | 2 (13%) |

| | |
|---|---------|
| Provided advice about other health issues | 4 (27%) |
|---|---------|

Do families have unmet needs regarding health visiting?

Five parents (21%) indicated that they received enough support from their health visitor, and therefore did not require further support; all these parents had received visits in the previous 12 months. Eleven parents (46%) indicated that they did not need additional support from their health visitor because they received support from other professionals; seven had had visits in the previous 12 months, four had not. Eight parents (33%) indicated that they needed additional support from their health visitor; four of these parents had had a visit in the last year and four had not.

Free-text comments were invited, and were provided by 15 respondents. There were three main themes in these comments:

1. Experiences of health visiting
2. Other professionals meet the needs of the child
3. More advice and support from health visitors is needed

Experiences of health visiting

There were mixed statements around parents' experiences of health visiting. Three parents stated that they had received support from health visitors soon after birth; one of these parents would have liked this support to continue, one parent felt that their child's needs were now better met by other professionals, and one parent had continued to receive

support from a health visitor with personal experience of Down syndrome, which was viewed positively.

“I would have appreciated more support from health visitors when [child] was a small baby. Support was good at first but then seemed to stop. It was very hard to get an appointment..... I didn't get any specialist advice about DS which would have been helpful”

Five parents highlighted negative experiences, including a lack of knowledge about Down syndrome from health visitors, a high turnover of staff and difficulty in getting appointments.

“The health visitor we saw about [child]'s 27month review knew nothing about DS & felt unable to conduct a development review or offer any advice. I felt she needed training to be able to provide relevant/appropriate advice.”

Other professionals meet the needs of the child

Six parents made statements indicating that other professionals met the needs of their child with Down syndrome, and therefore a health visitor was not necessarily needed.

“Our health visitor has provided limited support in the early weeks but we have not seen her since. However I do not feel we need any further support from her at present as our son's needs are better covered by more specialist professionals”

Two parents specifically mentioned their paediatrician as able to meet their child's needs, and three parents commented that their child was under the care of many different professionals so further support was not needed.

"We see paediatrician for annual check-ups plus audiology, diabetes, thyroid checks etc which covers health needs without health visitor"

More advice and support from health visitors is needed

Ten parents made comments under the theme of 'more advice and support from health visitors is needed'. Examples for the topic of additional advice and support were toileting, sleep, weaning, developmental checks, and access to services such as speech and language therapy.

"Advice on toileting & developmental checks would be useful. No obvious other sources for this post-portage"

"It would be helpful to have more assistance with navigating health & early years education. For example we have twice had medical referrals rejected because incorrect information has been supplied when in fact [child] met the threshold for referral"

Some parents also stated that having a health visitor as an additional source of advice and support would be useful despite being under the care of other professionals such as GP and paediatrician.

Discussion

As providers of a universal service to conduct health and development reviews and also to provide assessment and support for children with additional needs, the role of health visitors has the potential to be particularly important for families of children with Down syndrome. This exploratory study aimed to understand parents' experiences of health visiting for their child with Down syndrome. The findings indicated that not all parents of young children with Down syndrome received ongoing health visiting services and that some parents needed additional support.

In this study, 15 parents (63%) had received a visit from a health visitor within the last 12 months. The majority of parents had received one visit, and the most common activity was weighing the child, as reported by 60% of parents who had received visits. Advice was also provided, and some parents also received referrals to other services. It is noteworthy that eight of the nine parents who had not received a visit in the previous 12 months had children aged three years or older. This may be because the final universal key visit conducted by health visitors is scheduled to take place when the child is aged 2.5 years. Importantly, families are still entitled to health visiting support as needed until their child is 5 years old. However, these preliminary results suggest that further research is needed to understand support for families with older preschool children with Down syndrome.

Families with children with Down syndrome express a need for consistent relationships with key professionals (Marshall et al., 2015, Muggli et al., 2009). Only thirteen parents (54%) in this study knew who their health visitor was. Although not a statutory requirement, it may

be beneficial for parents of children with Down syndrome to have a named health visitor where possible, to facilitate a trusting and effective relationship.

Children with Down syndrome experience a greater burden of potentially serious health conditions and inequality in accessing the necessary health services, particularly in the early years (Dawson et al., 2014, Geelhoed et al., 2011, McCabe et al., 2011). Therefore it is important that health services identify and treat potential health issues to minimise costs and long-term impacts. As a universal service operating in the community, health visiting could be well-placed to contribute to these aims. Although five parents (21%) indicated that they were receiving enough support from health visitors, eight parents (33%) reported that they needed more support. Analysis of free-text comments showed that parents would particularly welcome advice on key aspects of development such as toileting and weaning, and support with service navigation. This mirrors findings from studies that have found that the early provision of information about Down syndrome and available support and services is highly valued by families (Douglas et al., 2016, Muggli et al., 2009). Some parents also noted that health visitors may need additional training about Down syndrome. This is consistent with findings that health visitors would value training for developmental disorders such as Down syndrome (Authors, under review) and autism spectrum disorder (Ibesaine, 2018).

Eleven parents (46%) indicated that they did not need additional support from a health visitor as they were being supported by other professionals, such as their paediatrician.

Health visiting services in England have undergone changes in recent years, with increased

workloads and support for some vulnerable families being reduced (Peckover, 2013, Greenway et al., 2013). These findings suggest that for some parents, although support from health visitors may have decreased, they are receiving sufficient levels of support from other services such as paediatricians or GPs.

This study only included families from one support group, and had a small sample size, limiting the generalizability of the findings. The questionnaire was purposefully designed to be short and simple to complete, and therefore there are limits to the data. The questionnaire asked parents to indicate how many times they had 'seen' their health visitor; however families may have had telephone contact with their health visitor, which would not be captured by this question. For those parents who indicated that they were not receiving support from their health visitor but were receiving support from other professionals, this study is unable to distinguish between those families for whom this was a shared and positive decision and those families who were unable to access health visiting independent of need. However due to the lack of research evidence in this area, this study provides valuable preliminary evidence about health visiting services for children with Down syndrome.

[Key questions for future research](#)

This study focused on parents' experiences of health visiting and the input they have received from health visitors. To go beyond the preliminary data presented in this study and consider the characteristics, needs and experiences of families in more detail, a qualitative interview study would be a valuable addition to the literature. Health visitors also contribute

to the care of children through other means such as multi-disciplinary meetings and liaising with other professionals. Future research should survey health visitors to explore the volume and type of work carried out to support children with Down syndrome, which parents may not be in a position to report.

Children with Down syndrome are often under the care of many health services (Schieve et al., 2009), of which health visiting is one. As some parents indicated, many professionals were involved in their child's care and could better meet their child's individual needs than a health visitor. Therefore future research needs to consider health visiting for children with Down syndrome in the broader context of health service provision.

Conclusion

Due to the increased prevalence of health issues in Down syndrome and the impact on long-term child and family outcomes, healthcare services need to be aware of, and responsive to the needs of children with Down syndrome. Health visitors can provide crucial support in the early years of childhood, but this exploratory study suggests that not all families receive this support despite unmet needs. It is important to understand what support parents receive across the spectrum of healthcare services, and how all healthcare professionals, including health visitors, can be supported to improve health outcomes for children with Down syndrome.

Key points

- Young children with Down syndrome are more likely to have serious health problems than the general population.
- Some parents of children with Down syndrome would like more support from health visitors, including advice about development and referrals to other services
- Parents of older preschool children with Down syndrome may be less likely to receive support from health visitors
- Further research is needed to understand health service provision for young children with Down syndrome from different professionals, and how health visiting fits into this landscape.

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