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Reassurance or judgement? Parents' views on the delivery of child health surveillance programmes

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Background. The first year of a child's life is a crucial time for child development. Current guidance about child health surveillance and health promotion programmes emphasises a partnership approach between health professionals and parents when it comes to child health care. Parents' voices have been largely absent from discussions about local child health programmes. For partnership working to be effective and for local services to be able to evolve effectively parents' views are vital.

Objectives. This study aimed to explore parents' views on the child health surveillance and health promotion programmes offered during the first year of their child's life. The study aimed to be consumer-led through the involvement of lead parents in all stages of the research process.

Methods. This study employed a qualitative methodology of focus groups and individual interviews. 35 participants were drawn from three general practices using a snowball sampling technique. Eligibility was determined as parents with a child under the age of one year or expecting a baby within the study timescale and registered at one of the 3 general practices. Focus groups were led by three 'parent-researchers' and individual interviews were conducted by a researcher. All focus groups and interviews were tape-recorded, transcribed and analysed using Atlas.Ti.

Results. Several main themes were identified in this study. Firstly, when discussing scheduled health checks for children under one year of age parents expressed more positive feelings for the eight-week check which was seen to be comprehensive and informative rather than the eight-month check which was viewed as bureaucratic and less reassuring. Secondly, parents clearly articulated a need for reassurance and support from health professionals involved in child health surveillance and health promotion programmes. Thirdly, a crucial professional in the delivery of these programmes was the health visitor. Whilst parents expressed support for the concept of health visitors some health visitors were seen as bureaucratic and as making judgements of need based on socio-economic factors. Finally, some parents spoke of feeling excluded from accessing support as they were deemed not to be 'in need'.

Conclusions. Wider concepts of partnership working between health professionals and parents, and, needs assessment are important to this study. Crucial elements of the partnership appear to be missing and this coupled with needs assessments that leave parents feeling excluded mean that there are discrepancies between expectations and experiences of parents. These issues require consideration in order to improve services and experiences.

Keywords. Child development, child health services, health promotion, parent, qualitative research.

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Introduction

The first year of a child's life is a crucial time for child development.[1,2] Child health surveillance (CHS) was originally devised early in the twentieth century, in response to high infant mortality rates and governmental recognition of sub-optimal child health status.[3] It developed in an ad-hoc fashion and by 1986 Butler's[4] independent review described the scope of child health surveillance as encompassing an overview of physical, social and emotional health, immunisation and health education, all from individual, community and public health perspectives. Since then, the need for increased focus and definition[4] and changes within both the child population and methods of service delivery, has led to CHS undergoing a 'decade of change',[5] outlined in the series of authoritative 'Hall Reports'.[5–7]

Today CHS is increasingly described as focusing on secondary prevention—detecting problems in child health and development. It is accepted as forming only one component of child health promotion which recognises that health is a product of complex interactions between social, physical and psychological factors. 'Modern' child health promotion, and CHS, emphasise the importance of relationships formed between professionals and parents and of equality of access to services as means of diminishing health inequalities.[5] Within this approach, there is an assumed element both of universality, with CHS providing a platform through which all parents could form such relationships, and of targeting, in providing an opportunity to identify those who need additional support. The tension between universal and targeted provision in preventive care is a matter of international debate,[8–10] with a common need to ensure that scarce professional resources are used to best effect in the reduction of health inequalities, whilst ensuring all those who need help are identified as early as possible. Further, the primary purpose of CHS varies from one country to another, being inevitably viewed 'through a disciplinary lens'[1] that may focus on child protection,[8,9] identification of developmental delay[5,11] or a perceived need for parenting support.[2,12]

In England, new guidance in the form of a national service framework (NSF) for children's services[13] continues to emphasise the approach cited in The Hall Reports,[5–7] which advocate parental involvement and partnership working. Such a model aims to recognize and build upon the unique knowledge that parents can bring to the assessment of child development, in combination with a minimal number of scientifically proven and justifiable screening tests.[11] The intention of this partnership approach is to work towards everyone's interests: maximising the autonomy of individuals and minimising medical intervention.

However, whilst parent bodies were included in the Executive Working Groups of the NSF, little attention has been paid to the inclusion of parents in shaping or evaluating CHS at a local level and parents' voices have been largely absent. In light of the continued endorsement of a parent-provider 'partnership' this is needed.

Methods

This study aimed to examine parents' views of child health surveillance and health promotion programmes offered during the first year of their child's life—a crucial time for CHS.

Unique to this project was the involvement of parents as 'insider researchers' to add credibility and understanding that enables participants to discuss openly their thoughts, leading to more robust data. Our three 'parent researchers' underwent specially designed training on research and focus groups to offset risks of inappropriately assumed knowledge or inadvertent leading/biasing data and were involved in all aspects of the research design, data collection and analysis and dissemination.

Study participants were parents registered with one of three designated general practices, with a child aged one year or under, or were currently pregnant and due to deliver before May 2002. The designated general practices were all in inner London, a city which shares common features with much of the developed world. Despite being geographically close, the three practices were characterised by differing levels of deprivation, by ethnic and social composition and by levels of identified health needs. The aim was not to recruit a representative sample, but to purposefully select informants who could provide a range of perspectives. We made a positive effort to include parents who are traditionally 'hard-to-reach' or reluctant to engage with services, including the use of incentives (£20 supermarket vouchers) to enhance participation.

Parents were recruited using 'snowball' sampling,[14] referral by GPs and health visitors, approaching parents at parent and infant groups and antenatal clinics, information mail outs and posters in key sites. 35 participants (34 mothers; 1 father) participated in either one of five focus groups ($n = 18$), an individual interview ($n = 12$) or a brief interview in a clinic setting ($n = 5$). Participants represented a wide range of socio-economic backgrounds reflecting local diversity.

All interviews and focus groups were tape recorded and transcribed anonymously. Data were examined using coding methods described by Strauss and Corbin.[15] Themes were established by the research team and then examined in more detail using Atlas.Ti.[16]

Results

This study identified core themes in the following areas: experiences with scheduled health checks; parents' expectations for reassurance and support; parents' relationships with health visitors; and the nature of needs assessments.

Scheduled health checks

When discussing their experiences of 'milestone' developmental checks, parents were more positive about the 8-week check than the 8-month check. The 8-week check was regarded as comprehensive and medically informative, providing reassurance to the parents about the biological indicators of their child's health. The 8-month check was viewed less favourably and commonly criticised as being overly bureaucratic, with numerous references about health professionals 'ticking the boxes', and lacking the detail of the earlier health check.

> "I felt that the 8-week check was very thorough. I went to my practice and the doctor was involved and it was very scientific—checking through the hips, the abdomen, the length of the legs, the weight . . . it made me feel very good that there was a knowledgeable professional person fully for my attention . . . But there is a huge contrast to the 8-month [check when] I saw a health visitor who was lovely, but was very much the sort of: 'Is he doing this? Is he doing that? OK, right—tick, tick. OK, let's just give him this cube, passes it from one hand to the other, puts it in his mouth, fine . . . OK you're done'. And it was about 5 minutes! She didn't even ask to take his clothes off, or have a look at him." (Focus group participant)

The 8-month check failed to impress parents both as a medical evaluation and as an opportunity to address parenting concerns, whereas the 8-week check satisfied parents desire for both and offered parents 'reassurance and support' at a vulnerable point.

Reassurance and support

Parents sought reassurance that their child was developing in a 'normal' way and meeting anticipated developmental markers. However, it became clear that they are also looking *beyond* biological indicators (such as height, weight, movement) and wanting to gain a sense of confidence in their 'parenting' skills and to increase their knowledge about dealing with common childhood ailments. For a number, this was amplified by their position as first-time parents, without traditional support networks that would aid in their adjustment to a new role.

> ". . . it would be nice to have something [to] say [to] . . . 'oh my goodness this baby's screaming at 6 o'clock every night. Oh, okay, it could be colic, oh all right then, I could try 'Infacol' or I could try rubbing his back' or whatever." (Focus group participant)

However, the ability to ask for support and reassurance was sometimes difficult and, even when this was articulated, could go unrecognised.

> "I was really struggling, very, very tearful and I said: 'I am not having a very good time at the moment'. 'You're doing fine, dear' she [the health visitor] said and patted me, and left. And I was really struggling at the time. I didn't get the support . . . Patting me on the shoulder and saying 'ooh' . . . and all I want to say is 'I want to have them fostered because I can't cope'. I got nothing from her at all." (Focus group participant)

Impressions of health visitors

What complicates the backdrop to scenes like these are the dynamics of the partnership between parents and health visitors. The health visitor was described as a key individual in shaping parents experiences of CHS. The *idea* of a strong relationship with a health visitor as a central feature of CHS was a positive one.

> "The concept of health visitors is fantastic—'cause you don't need to see a doctor all the time but you need some reassurance and you need a relationship with somebody who understands child development . . ." (Focus group participant)

Individuals who had a positive relationship with their health visitor felt she helped them to deal with an array of health and social issues for them and their child in the first year.

> ". . . there was a time when I actually got quite, quite down . . . but I found easier to talk to [the health visitor] rather than going to see the GP . . . [she] put me in touch with a support group for women who are feeling the same." (Individual interview)

An effective health visitor was not only 'a first port of call', but also a community resource, directing parents to a variety of services. These health visitors were depicted not as simply capable and dedicated, but also flexible, available and willing to support parents 'above and beyond' their remit.

However, in this study positive comments regarding health visitors were few in comparison to more negative comments. The majority of parents voiced strong dissatisfaction with the services they received from health visitors. Rather, instead of receiving reassurance and support, parents often felt that they were being judged, either on 'appearances' or on markers of socio-economic status (SES).

> ". . . you can tell instantly if someone is from a comfortable background or they are in a struggle, are they on their own? do they have support? is the baby dressed nicely? are there nice things in the house? And immediately they make that judgement . . ." (Focus group participant)

> "... she arrived on my doorstep absolutely while I [was] walking out to do the school run, and I said: 'I have to do ... the 8 week check for you?'. To which she said to me, 'Oh I knew your baby was all right'. I have to say I ... turned around said to her, 'You wouldn't have had a clue if I had buried her in the garden!' (Focus group participant)

Furthermore, parents often perceived health visitor contacts as unnecessarily bureaucratic and many described the content of their interactions as inappropriate, consisting of a high degree of 'box ticking'.

> "[I said] 'I have to point out that I am ticked off ... you're here to fill in your forms and not to check my baby.' Off she went sort of looking at me as though I was horrible." (Focus group participant)

In addition few parents had an understanding of the training and expertise of health visitors or of partnership approaches to child health care. This lack of understanding may contribute to contradictory expectations and difficult interactions between health visitors and parents.

'Needs assessment'

The guiding principle in CHS traditionally has been one of universal service provision, with a targeting of increased input to particular groups. Faced with increasing demands, there is a growing emphasis within CHS programmes to target services to ensure the greatest coverage possible within areas of social deprivation. That social and economic deprivation is often accompanied by health risks and deficits remains undisputed.[17] However, parents in our study who did not exhibit obvious signs of deprivation stated that they felt judged, determined to be 'low risk' and excluded from accessing the support they needed. This sense of exclusion seemed to hinge upon less tangible factors such as social isolation and absence of familial support networks which did not appear to be considered in the health visitors' assessments.

> "I felt they [health visitors] prioritise people in financial means, and [the] more needy and also those who have lack of support which is sometimes understandable and sometimes not ... I think if I had appeared very upset and nervous, she would have stayed ..." (Focus group participant)

Parents in the study who had long-established social support networks in the community (often extended family systems) articulated less need for this type of reassurance but they did want more practical assistance such as advice on tackling issues of housing and access to services.

Discussion

The effort to promote a partnership between parents and professionals is progressive and seeks to recognise parents' skills. However, this was not the reality experienced by parents in this study. Our findings suggest that what parents expect and want regarding CHS is different to what they experience and receive.

Partnership

Efforts towards the development of a 'partnership' between health providers and parents were often not implemented successfully at a local level with key elements and shared understandings missing. This has created a situation in which parents appear uncertain of the validity of services and dissatisfied with quality. Within this climate of misunderstanding there is little chance of realising an effective partnership model: *if parents know little of their role as 'partners', they will subsequently look to providers for a very different service*.

Health visitors are vital to the delivery of CHS and the validity of the concept is not doubted. However, our findings suggest that parents and health visitors are working at cross-purposes with respect to CHS. Apart from specified CHS contacts, health visitors have been urged to initiate contact with parents only if specific needs have been identified[18] and informed that, using normative definitions of population need, their services should be concentrated in areas of 'deprivation'[19] and on 'those in greatest need.[20] Parents also have been encouraged to take the initiative when they are concerned about their child rather than wait for the professional to make contact. However, this assumes parental confidence in doing so and some evidence from health visiting research[21,22] suggests that parents are unlikely to initiate contact when they do not have established relationships in place.

Partnership working requires skilled communication, recognition of fluctuating needs and services based on a trust relationship.[21,23–26] Only when these conditions are in place will parents feel sufficiently secure to reveal their 'real needs'[22] and concerns that may be of great significance to their child's future health and development. Similar working conflicts have surfaced in a different form in other local studies in England[27,28] and overseas,[29,30] with policies seeming too inflexible, at times, to meet the variety of individual perceptions and needs that may arise in practice.

'Needs assessments'

There is an established and demonstrable benefit to providing specialised and/or additional services targeted at areas of social deprivation. Vulnerabilities may translate into greater health risks and greater difficulties in accessing appropriate health care. This paper does not seek to undermine the existence of specialised services within the community, but our findings suggest that parents without obvious markers of socio-economic need have felt excluded from the negotiation of CHS, leaving them understandably critical of the system.

The hazards of family life, such as domestic violence, separation and divorce of parents, sexual abuse and maternal post-natal depression, occur across all social groups. Services which recognise and link these issues with lower socio-economic groups run the risk of stigmatising entire portions of the population, while under-serving others due to faulty assumptions that they are 'risk free'. The definition of need is complex.

Conclusion

This study highlights important questions about the delivery of CHS. The results call for parenting support, especially during the first year of a child's life, to be a legitimate right for all, across social and demographic categories[12] and for factors influencing partnership success to be more fully understood.

A key issue for further research is whether parents' dissatisfaction with health visiting stems from individual professional practice or the constraints under which health visitors are placed.

Limitations

The small sample size of this study may impact on the generalisability of our findings. However, qualitative research is concerned with generating insights that may be useful in different settings, because the understanding they generate is clearly applicable elsewhere; this form of generalizability differs from that gained through statistical studies. Also, the sample incorporated an array of views from various socio-economic groups, life experiences and backgrounds, including ethnic and minority groups that make it seem potentially applicable in other settings. It was clear during data collection that 'data saturation' was achieved.

More importantly, the views of health visitors are missing. In order to realistically establish a 'partnership' framework for CHS, there is a need to examine health visiting role, demands and constraints. A follow up study of health visitors in the local area aims to do just this.

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Conflicts of interest: none.

Contribution of authors

NS, MM, PS & AS obtained the funding for the study; All authors planned the study once funding had been obtained; BR, PS, DA & SF collected the data via interviews and focus groups; All authors were involved in data analysis; BR, SC, NS & AS wrote the paper; All authors commented on drafts and the final version.

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