# Lay workers for improving the uptake of childhood immunization

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Karen Whittaker is Senior Lecturer, Department of Nursing, University of Central Lancashire, Preston, UK There is currently much public concern over and loss of faith in childhood immunization (Owens, 2002). This is reflected in numerous commentaries in the popular daily press (Dixon, 2002) and, more worryingly, the evident decline in uptake of childhood immunization (Department of Health (DH), 2001; Owens, 2002).

There is also a growing appreciation of the potential benefits of consumer involvement in health-care decision making (Allen, 2000; Health Technology Assessment, 2002), which has been advocated globally by the World Health Organization (WHO) and Unicef (1999) for the improvement of family and community practices that favour better child health outcomes. In Britain, contemporary public policy includes strategies for increasing local participation in community life, in the hope that this will foster the development of a healthier environment. Examples include Sure Start (Department for Education and Employment, 1998) and the Active Community Challenge, supported by the Home Office Active Community Unit (Active Community Unit, 1999) to promote volunteering in the community.

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## ABSTRACT

The aim of this review was to identify whether non-professional volunteer support might be effective in improving the uptake of child immunization. The Cochrane Library, Medline, Cumulative Index to Nursing and Allied Health Literature and Embase databases were searched for randomized controlled trials comparing groups of parents supported by lay volunteers with those supported by conventional child health services. Two such trials met the review criteria. These studies suggested that using non-professional volunteers to support parents can be an effective strategy for improving the uptake of immunization in children younger than 2 years, but there is limited evidence to suggest that this effect is sustained for older children. Equally, intervention effects could, because of differing cultural and sociodemographic factors, be less marked when applied to British populations, in which the parents of preschool-aged children have access to immunization support from a generic health visiting service. Those leading Sure Start initiatives have been encouraged to incorporate community development, a multifaceted strategy that, as Cowley (1999) explained, can promise 'added value' for most interventions but which lacks an empirical evidence base proving its worth in terms of health outcome. Lay or user involvement in care delivery can, however, be identified as one component of a community development approach and, as a single component, could be tested for effectiveness using an experimental design.

Given the suggestion that herd immunity to infectious diseases is currently under threat, causing the British government actively to promote the uptake of immunization (Kmietowicz, 2002), it seems reasonable to investigate whether lay involvement can be used as an effective intervention to increase the rate of immunization. This mini-review, using methods outlined by Griffiths (2002) and Sackett et al (2000), therefore aimed to identify whether the involvement of lay workers in community child health services is effective in improving the uptake of childhood immunization.

#### Method

The question under investigation is one of effectiveness and as such warrants being judged by research involving randomized controlled trials (RCTs) (Dixon, 2002). Studies using an RCT design were selected for this review above other designs on the premise that, if such studies are properly conducted, the randomization of subjects to control or intervention groups should minimize selection bias. In addition, the prospective nature of the RCT design ensures that data are collected on events as or soon after they occur (Greenhalgh, 2001). A limitation of this design is that, as a result of the ethical difficulties inherent in denying control groups pre-existing services, it does not always lend itself to measuring the effectiveness of social interventions. These problems can, however, be remedied when new social support services are developed, offering interventions in addition to conventional provision, since a control group can exist without compromising service provision, as is the case here.

Trials were included if the intervention studied included lay or non-professional workers as a source of support for parents in the community and if the comparison was made with a control group receiving only conventional child health services. Studies that had goals beyond the uptake of vaccination were included provided that some measure of vaccination uptake was reported. The scope was limited to those papers written in the English language and those published in journals readily available to the author (i.e. held in the libraries of King's College London or the University of Central Lancashire, Preston).

#### Search strategy

The Cochrane Library, Medline (1966–present), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1984–present) and Embase (1980–present) databases were searched. *Table 1* shows a list of the free text and index terms used. To improve the sensitivity of the search, truncation (e.g. immunis\$), wild card options (e.g. non?professional) and alternative American spellings were used with free text searching, and medical subject headings (MESH) were 'exploded' to include all subdivisions or subheadings of the term. Synonymous terms were combined using the OR operator, generating three sets of searches that were then combined using the AND operator.

From a total 75 citations, only four studies (Johnson et al, 1993; Fitzpatrick et al, 1997; Barnes et al, 1999; Johnson et al, 2000) met the review inclusion criteria when the titles and abstracts were reviewed. It appeared that a large proportion of the citations were for papers involving volunteers or social support in some form but not volunteers or lay workers delivering a care intervention.

On inspecting these four papers, two (Johnson et al, 1993; Barnes et al, 1999) reported the results

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#### Table 1. Search terms used in the study

	Problem of interest		Intervention		Outcome
Question components	Uptake of childhood immunization		Community lay support childhood immunization		Improved uptake of
Facets	Child immunization		Lay support		Immunization
Search terms	Child\$	A D	Lay support OR Non?professional OR Peer support OR User-involvement OR Lay participation OR Lay workers OR Community parent\$ OR Community mother\$ OR Home-start OR Home-start OR Volunteer support NESH terms Peer group Social support Voluntary workers	A D	Immunis\$ Immuniz\$ Vaccina\$ MESH term Immunization programs

'The studies were concerned with families with young children who were scheduled to receive primary courses of childhood vaccination and who were living in economically deprived communities. ' from RCTs, the other two being extensions of the Johnson et al's 1993 study. One was a 7-year follow-up of the trial sample (Johnson et al, 2000) and the other a prospective study of the support of 'community mothers' for a travelling community, which was then compared with previous RCT groups from the non-travelling community (Fitzpatrick et al, 1997). Fitzpatrick et al (1997) was excluded as the new cohort could not be easily compared with those participating in the earlier RCT owing to differences in their respective cultural and sociodemographic profiles.

#### Assessing the quality of the evidence

*Table 2* summarizes the key features of the final papers: Johnson et al (1993) and Johnson et al (2000) considering the Irish 'community mothers' programme, and Barnes et al (1999) describing an American scheme. Although there are some limitations, they are capable of giving answers to the

questions posed with a limited risk of bias.

Both studies were original, Johnson et al's assessing the effectiveness of non-professional volunteers in delivering a child development programme, and Barnes et al considering the impact of volunteer support specifically on childhood immunization. The studies were concerned with families with young children who were scheduled to receive primary courses of childhood vaccination and who were living in economically deprived communities. Johnson et al's (1993) study specifically involved first-time mothers living in Ireland, whereas that of Barnes et al (1999) involved either parent of similarly aged children living as part of a New York immigrant community from the Dominican Republic. The cultural and possible gender differences of the parents receiving the intervention have the potential to influence the study outcome and should therefore be considered when then translating the findings to a British context.

	Johnson et al (1993, 2000)	Barnes et al (1999)		
Sample	First-time mothers $(n = 267)$ living in a defined geographical location and recruited to the RCT, 77 participating in the follow-up	Families $(n = 163)$ with children under 2 years of age who were registered patients of an identified medical centre and had not attended the immunization clinic or were due or overdue for vaccination		
Design	RCT	RCT		
Intervention	Support from experienced volunteer mothers who had received 4 weeks' training in the delivery of a child development programme	Community volunteers providing immunization education and information about vaccination schedules via home visits and telephone calls. Volunteers also contacted clinics and provided an escort for appointments		
Length of intervention	The 'community mother' visited families once a month for the first years of the child's life	Community volunteers visited families when they enrolled on the study and then offered home visits and telephone calls as required for up to 6 months		
Control	Standard support from the local public health nurse	Visit on enrollment by a control group interviewer who was informed of the child's immunization status and instructed to reschedule any missed appointments		
Data Interview with the family collected development nurse on first birthday and 7 years later. Training for and format details of interview not given		The control group interviewer and the community volunteer (for the intervention group) collected data 6 months after enrollment. Both were trained by the study director and used scripted interview formats		

#### Table 2. Description of the studies included in the review

The Irish study used volunteers (so-called 'community mothers') to support mothers' general care of their new infants, in anticipation that this would affect a range of child health and development outcomes. The American study used volunteer support to focus parents' attention on childhood immunization. The interventions were similar in as much as they involved additional support provided by non-professionals, but they differed in focus, duration and intensity. Similarly, the experience of the control groups differed, the control group mothers in the Irish study receiving more contact as part of their standard care than the American control group parents. When comparing these standard support services with British generic health visiting support, closer parallels can probably be drawn with the Irish than the American situation.

Neither of the papers reporting the Irish study (Johnson et al, 1993, 2000) provided details of how the information on immunization was collected, whether simply via the questionnaire used during interview conducted by the family development nurse, or by a review of medical records and/or a health authority immunization database. This is important because each method has limitations in terms of accuracy and completeness. The American study was more helpful here, clarifying that parent-held records were used as a source of information. The rationale given for using these records was that their accuracy was anticipated to be important to parents because they were also used as 'proof' of vaccination if parents wished to use school or holiday childcare clubs.

Greenhalgh (2001) indicates four types of bias that can affect the outcome of controlled trials: selection, performance, exclusion and detection.

#### Selection

Johnson et al (1993) used a table of random numbers to randomly allocate their participants to the control and intervention groups. Barnes et al (1999) arguably randomized their study participants too early, i.e. before the participants had consented to the study. Early randomization can adversely affect an 'intention-to-treat analysis' as those who have not consented to the study should still be included in the analysis because they were part of the sample originally identified (Hollis and Campbell, 1999). Although Barnes et al did not appear to use an 'intention-to-treat analysis' as recommended (Begg et al, 1996), they gave an account of the demographic details of those refusing to participate in the study, who did not differ greatly from those who consented. Although it is impossible to be certain, this suggests that the results have not been biased by systematic differences between participants and non participants (for example participants being more or less likely to respond to the intervention).

#### Performance

Performance bias refers to the fact that the behaviour of participants or investigators may alter the outcome simply because they are participating in a study. So it is important that the effect of the research process itself (as opposed to the intervention under study) is as small as possible and affects both groups equally. There is no indication of bias in either study, but it should be noted that there was, in the Irish study, limited discussion of the amount of contact that mothers had with volunteers and public health nurses. This makes it difficult to judge whether conventional care was altered in any way that would bias the outcome.

#### Exclusion

Exclusion bias occurs when participants drop out of the study for reasons that may be related to the outcome of interest. Exclusion bias may be present in the American study; 21% of the intervention and 10% of the control group children were lost to follow-up. The within-group comparison of these lost versus those retained showed only one difference: the control group children were older on enrolment than those lost to follow-up (9.0 versus 6.5 months). The authors of the Irish study account for all the losses, with 11% of the total sample being lost to follow-up at 12 months. The proportions were similar for each group (10% for the intervention and 13% for the control group; Johnson et al, 1993), therefore the groups remained comparable.

#### Detection

Finally, bias in terms of detection might have been possible in the Irish study, but, as previously stated, this was difficult to determine as there was insufficient detail on how information on immunization was collected.

Both studies appeared to give sufficient time for follow-up since data were collected at least 3 months after an opportunity for vaccination to take place.

#### Results

The main study results and the tests used in each study are shown in *Table 3*. Johnson et al (1993) reported that 20% more children in the intervention

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	Johnson et al (1993)	Barnes et al (1999)	Johnson et al (2000)
Analysis	Relative risk of an incomplete vaccination schedule at child's first birthday	Relative risk of a more than 30-day vaccination delay during follow-up (mean 6.5 months)	Relative risk of an incomplete vaccination schedule by child's 8th year of age
Outcome measures	108 (85%) intervention vs 68 (65%) control group children up to date with vaccination ( $p$ < 0.001); RR = 1.31 (95% CI 1.21–1.54)	42 (75%) intervention vs 41 (54%) of control group children up to date with vaccination (p < 0.05); RR = 2.8 (95% Cl 1.21–6.54) for delay	MMR uptake in 36 (94.7%) of intervention vs 37 (100%) of control group children ( $p$ =0.15); RR=0.95 (95% CI 0.88–1.02). School booster uptake in 38 (100%) of intervention vs 35 (94.6%) of control group children ( $p$ =0.15); RR=1.06 (95% CI 0.98–1.14)

#### Table 3. Statistics used and study findings

group than in the control group had completed their primary immunizations. The relative risk (RR) for uptake in the intervention group was 1.3 (95% confidence interval (CI) 1.21-1.54), meaning that the intervention group children were 1.3 times more likely than the control group children to have completed the primary course by their first birthday. Barnes et al (1999) reported a similar increase in the proportion of children who were up to date with their immunizations, 75% of the intervention vs 54% of the control group children being fully vaccinated 6 months after enrolment to the study. These differences were statistically significant. Control group children were 2.8 times more likely to be delayed in terms of immunization by the final visit than were intervention group children (RR=2.8; 95%, CI 1.21-6.54).

The 7-year follow-up study by Johnson et al (2000) reported that the RR for intervention group children who had the measles-mumps-rubella (MMR) jab was 0.95 (95% CI 0.88–1.02), and that for those taking the school booster 1.06 (95% CI 0.98–1.14). This indicates that there was not a significant long-term difference between intervention and control groups. However, only one-third of the original sample was followed up, and the uptake of vaccination in both groups was very high, allowing little scope for improvement in the intervention group (*Table 3*).

#### Conclusion

These two studies suggest that, among those families receiving non-professional voluntary support, children less than 2 years old were more likely to be up to date with their immunizations. There was no evidence of any longer-term effects of nonprofessional support, but the evidence is extremely limited as the findings were based on less than half of the original study sample (Johnson et al, 2000). These studies have some limitations but nevertheless provide robust evidence that lay support can be effective in increasing the uptake of vaccination.

It is, however, crucial to note that interventions such as these are difficult to separate from the context in which they are delivered. In the USA, primary health care for deprived communities can be extremely limited, so any additional intervention might easily improve the outcome. These findings were replicated in Ireland, where the control group received routine public health nursing support (at least two visits in the 6 weeks after birth), providing more confidence that lay support did indeed provide a benefit over and above that delivered by standard professional care.

In both studies, the baseline uptake of vaccination in the early years (as measured by the rate in the control group) was very low compared with that of most communities in the UK. The target populations in both studies were selected on the basis of deprivation. Such interventions might be worth considering in the UK if a low uptake of vaccination is associated with deprivation. These studies do not, however, provide evidence to support the use of lay people in rectifying a declining vaccination rate in which the main issue is a motivated decision not to vaccinate, as appears currently to be the case for MMR vaccination.

The loss of twice as many children in the intervention group than the control group within the American study children also raises questions of parental acceptability of the intervention. If parents perceive the intervention to be unacceptable, they are more likely to refuse to cooperate and accept contact with non-professional volunteers even if the intervention is able to produce an effect. The issue of client acceptability of the service warrants further exploration and would be an important factor if deciding to invest in a new provision of care.

This mini-review does not address all the issues involved in determining the effectiveness of nonprofessional/lay volunteer support for parents presented with decisions about how, when and whether they should offer their young children immunization. Research evidence using robust RCTs is limited, making it difficult for practitioners to arrive at a firm conclusion about the relative merits of this approach for health care. The decision to limit this review to RCTs theoretically limits the range of interventions that might be studied, although the searches did not identify controlled studies of other interventions, making it is unlikely that there is a large number of studies of effectiveness that have used other designs.

This review concludes that such evidence, as it exists, strongly supports the effectiveness of lay intervention. Although the effects of volunteer support might have been small (as sample sizes were small and confidence intervals wide), no harmful effects were identified. Vaccination uptake was but one outcome studied in the 'community mothers' programme, which demonstrated positive outcomes in terms of a range of measures. Such programmes might also deliver other benefits. The involvement of local volunteers to supplement existing core provision could, for example, be an effective way of improving cultural relevance. These outcomes have not been (nor are likely to be) examined in controlled trials.

It is possible that the effects could be smaller in Britain, where families already have access to home visiting professional support via generic health visiting, but these results are certainly encouraging enough to warrant further exploration, particularly for deprived communities.

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### **KEY POINTS**

- In the UK, there is currently much concern about falling vaccination rates.
- Lay involvement in health care may be a means of facilitating participation and delivering effective health care.
- Only a few studies have examined the effect of lay support on the uptake of childhood vaccination.
- The evidence reviewed here suggests that programmes of lay support might be effective in increasing the uptake of vaccination in deprived communities in the UK.
- There is no evidence to clarify whether lay involvement might be useful where low uptake is not related to deprivation, as is seen with the current decline in the rate of MMR vaccination.