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Reducing health inequalities: Ethical issues in a Scottish child health home visiting program

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Childhood inequalities have far-reaching consequences throughout the life cycle. Reducing health inequalities for children is an important goal for health policy, grounded in justice and the desire to prevent avoidable ill health. The purpose of this article is to report and discuss the results of a qualitative study into the ethical issues identified by staff involved in a paediatric home visiting program in Scotland. One of the major aims of the visiting program was to reduce health inequalities. The results presented here relate to two issues identified by study participants: conflicting responsibilities, and ethical tensions inherent in the very task of reducing inequalities. The requirement for evaluation, meeting targets and working with partners led to conflicting responsibilities for some participants. Working to reduce health inequalities led to some paradoxical effects, and a fear that root causes of inequality were not being addressed. These results suggest that programs aimed at reducing inequalities may lead to unexpected ethical tensions. Policy-makers and those implementing such programs need to be aware of possible unintended effects and tensions experienced by staff.

Key words: *Ethics, Health inequalities, Child health, Primary care interventions, Home visiting*

Reducing health inequalities is a key public health goal around the world. A major aim of many strategies is to reduce inequalities in the area of child health. Health inequalities in childhood have a far-reaching impact. Children born into deprivation have higher infant mortality rates, lower birth weights, lower breast-feeding rates, higher rates of both malnutrition and obesity, and higher rates of other diseases. The children that survive their infancy and early childhood continue to have higher morbidity and mortality rates than their better off peers, through their teens and on into adulthood (Child Health Surveillance Programme, 2004; Spurrier, Sawyer, Clark, & Baghurst, 2003).

These findings challenge policy-makers to identify and implement effective interventions to improve the health of disadvantaged children. Home visiting is currently considered to be such an intervention. A recent meta-analysis found home visiting to be associated with a range of positive outcomes including: higher rates of breast-feeding; a reduction in the frequency of unintentional injury; enhanced intellectual development; reduced child behavioural problems; improvements in the detection and management of postnatal depression; improvements in parenting skills; and enhanced social support for mothers (Elkan et al., 2000).

As part of their health policy to reduce inequalities in health, the Scottish Health Department introduced an intensive home visiting program, known as Starting Well, in two socioeconomically deprived areas of Glasgow in late 2000. The intentions behind this and other programs aimed at reducing health inequalities clearly have ethical dimensions. These revolve around the idea that it is unjust for some people to be more disadvantaged, for example with poor health, than others, especially when that disadvantage is undeserved. As health plays a pivotal role in our opportunities for other goods such as employment or education, redressing health inequalities has particular moral urgency. This paper briefly describes the Starting Well program and reports results from a study into ethical issues identified by Starting Well staff. The discussion links these findings to ethical implications for policy and practice.

Background

Scotland has the highest infant mortality rate in the UK and one of the worst life expectancy rates in the developed world (The Scottish Office, 1999). Thirty per cent of Scottish children are currently born into relative poverty (Brown, Scott, Mooney, & Duncan, 2002). Data from the Information and Statistics Division Scotland (ISD) identify specific

areas where poor health outcomes are associated with deprivation. Figure 1 shows the relationship between increasing childhood mortality and severity of deprivation for children under 20 years

Figure 1: Deaths by deprivation quintile (ISD 2003a)

Deaths by deprivation quintile; rates per 10,000 population in under 20 year-olds, Scotland, year ending December 2001
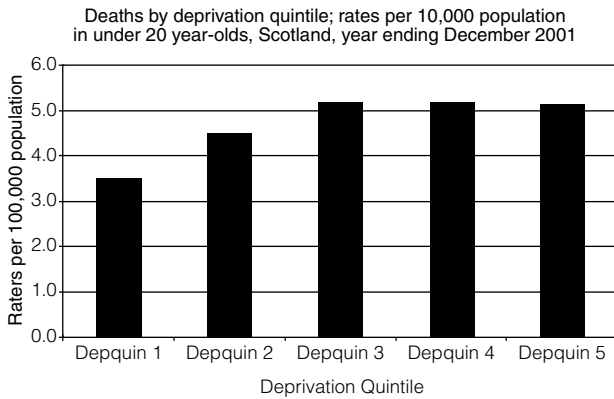
of age, for the year ending December 2001.

There are 3.5 deaths per 10,000 population recorded within the least deprived area (depquin 1) compared with 5.1 deaths per 10,000 population within the most deprived area (depquin 5).[1] The effects of deprivation are seen most clearly in the youngest and oldest age groups. For infants, prematurity associated with deprivation is a major cause of mortality. For children under the age of 15, death rates from unintentional injury are almost three times higher for the most deprived children compared with their most affluent contemporaries (ISD, 2003a).

Figure 2 shows the correlation between lower rates of breast feeding and deprivation. The correlation is strong across all maternal ages, with rates in the most deprived quintile being half of those in the least deprived (ISD, 2002).

Figure 2: Breast-feeding and deprivation (ISD 2002)

Breast-feeding recorded at the First Visit; by maternal age & deprivation
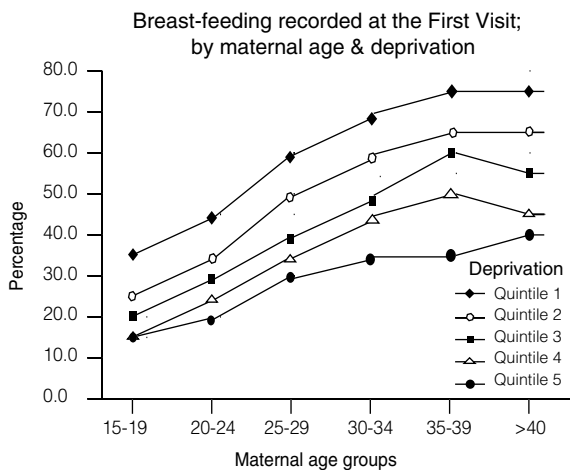

Figure 3 shows emergency admissions due to road traffic accidents by deprivation category (ISD, 2003b). There is a marked difference in the standardised discharge ratio across deprivation category. Rates for emergency admissions are three times higher in the most deprived area (146.0 in depcat 7) compared with the least deprived area (43.9 in depcat 1).

Figure 3: Emergency admissions of RTAs (ISD 2003b)

Emergency admissions for RTAs for children under 15 years of age by deprivation category year ending March 2002
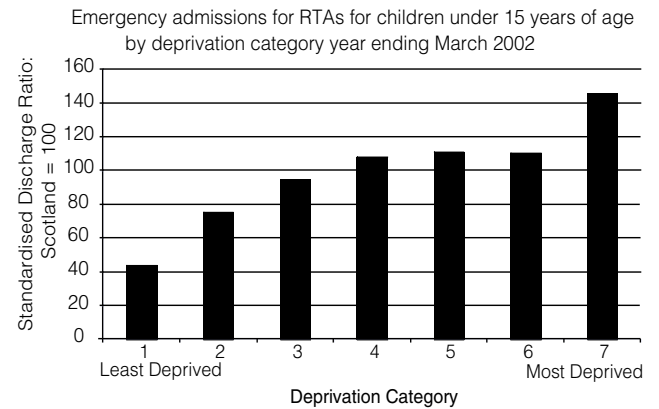
Starting Well

Against this background, the Scottish Health Department introduced a demonstration project of intensive paediatric home visiting called Starting Well, in order to reduce health inequalities for children and improve health outcomes. Starting Well was a three-year, £3 million initiative based in Glasgow, that piloted new ways of helping parents and young children achieve the best possible start in life. Starting Well was co-ordinated by the Glasgow Healthy City Partnership. The project was officially launched by the Minister for Health and Community Care in November 2000.

Starting Well aimed to demonstrate that child health can be improved by:

- Offering a program of activities designed to support families

- Ensuring parents and children have access to enhanced community-based resources (Starting Well, n.d.).

The specific objectives for child health included:

- Promoting children's health through a range of opportunities

- Reducing the adverse consequences of risk factors on children's health and wellbeing

- Improving opportunities for young children to socialise with other children.

For families, objectives included:

- Explicit attempts to improve parental self-esteem, psychological wellbeing, empowerment and achievement in the parenting role

- Enhancements in parental knowledge

- Increases in parental abilities to cope effectively with fundamental issues in parenting.

The project consisted of two arms—home-based support and community support. The home-based support consisted of intensive home visiting by health visitors, nursery nurses, and health support workers. Intensive home visiting was offered to all families with new babies in the project areas of Easterhouse in the east, and Govanhill and Gorbals in the south of Glasgow. Contact began in the early ante-natal period and focused on parenting issues and the provision of practical support, including the development of family health plans.

The second part of the intervention was strengthened community-based support. The aim was to provide a supportive local context for the family-based work. Local Implementation Groups were established in the project areas, with the aim of developing funded networks of community-based support services. These networks complemented existing services, and were integrated into existing local partnership arrangements.

The study

In 2002, I did an interview study that identified ethical issues encountered by staff working in two public health services in Scotland, one of which was Starting Well. The methods and overall results from this study have been reported in detail elsewhere (Rogers, 2004a). The results related to three central categories of ethical issues in public health practice: paternalism, responsibilities, and ethical decision-making. This paper reports on the sub-group of Starting Well data relating to conflicting responsibilities and to the ethical consequences of projects that explicitly aim to reduce inequalities. The data relating to inequalities and the Starting Well-specific results have not been previously published.

Methods

Permissions and ethics approval

Ethical approval was granted by the Greater Glasgow Primary Care – Community and Mental Health Research Ethics Committee. All participants gave written informed consent to be interviewed.

Participants

The sampling strategy aimed to access a wide range of roles and occupations. A list of staff was obtained from the Glasgow Starting Well Demonstration Project. This was used to generate a sampling frame with six cells, each representing a different role or profession such as health visitor, nursery nurse, medical staff, management staff, or public health consultants. In cells with only one person (e.g., a unique position), that person was selected. Random selection was used in cells with more than one person. Potential recruits were sent a letter, with telephone follow-up one week later. Recruitment letters were sent out in two rounds; the second round targeted cells with no recruit to date. Fifteen letters were sent out to Starting Well staff, leading to nine interviews. Recruiting stopped once I had requested at least one interview from each cell in the sampling frame.

Qualitative interviews

Interviews took place in late 2002, either at the work place of the interviewee or another place of their choice, and lasted between 35 and 90 minutes. Participants' responses were recorded in contemporaneous notes taken by the author, with additional notes written immediately afterwards. Material from each interview was entered onto computer within 24 hours, and checked against the original interview notes. The data reported here relates to participants' responses to questions about responsibilities and reducing inequalities. These topics were explored with open-ended and clarifying questions.

Analysis

Analysis involved coding the data into categories (Pope, Ziebland, & Mays, 2000). Coded material was compared and organised into themes that were then grouped into categories reflecting the major issues described by participants. Of the results reported here, the category "responsibilities" derived solely from the data, and the theme

"inequalities" derived from the theoretical concept of justice. To strengthen validity, the research findings were fed back to participants who attended presentations offered at three different venues (Malterud, 2001).

Results

Conflicting responsibilities

Starting Well staff described a number of areas in which they experienced conflicting responsibilities.

Service delivery vs evaluation

Participants described tensions between providing services for children, and collecting data for project evaluation. These tensions arose from the need for rigorous evaluation of the project, which in turn required health visitors and nursery nurses to follow specific project protocols. One example of this tension was provided by a participant whose project protocol required her to check that children at a certain age progressed to drinking from a cup rather than a bottle (an important milestone for oral health). The participant described arriving at a home in which a child was found tied into his pram wearing a dirty nappy. She could not see any drinks or food suitable for young children in the house. This participant felt that her major responsibility was for the immediate welfare of the child. Meeting this responsibility was incompatible with meeting her project responsibilities to follow protocols and collect the relevant data about cup and bottle drinking, with the result that there was an apparent failure in following the protocol and collecting data for evaluation.

Participants described another example of the tension between evaluation and service delivery, related to record keeping. Prior to implementing the project, and by tradition, the child health record generated by health visiting was kept by the family. Starting Well required health visitors to keep a family, instead of a child health, record. This record was held centrally for evaluation purposes rather than being held by the child's parent(s). Participants described this change as a challenge to their responsibility to keep the record solely for the benefit of the child.

Meeting targets

Participants described ethical tensions relating to meeting targets, such as decreased maternal smoking rates, increased breast-feeding rates and immunisation uptake, and registration with dentists by a certain age. Some participants described the targets as being driven by political pressures to show results as soon as possible rather than provide a meaningful evaluation of the project. They expressed concerns that the targets might not capture important practice as there was an undue emphasis upon process results, with the danger that claims would be made about success before this could be properly evaluated. These pressures were attributed to political timelines requiring quick results whereas some participants said that the true success of Starting Well would not be fully known until the children in the project became parents themselves.

Participants described particular features of the families they were working with that created barriers to meeting targets. A significant number of the mothers in the program had addiction disorders, which made the target for decreased maternal smoking rates almost impossible to achieve. For some families visited by study participants, registering with a dentist was not a priority when trying to survive domestic violence or the sequelae of criminal activities of some members of the family.

Some participants expressed fears that meeting the targets set by the project protocols could compromise professional values, by encouraging paternalism or coercion.

Working with partners

Participants described ethical issues raised by working with partners, including lack of shared professional values, inadequate standards of confidentiality, and conflicts of interest. Starting Well required health visitors to work with health support workers (drawn from the local community), who were employed through a project partner that provided services to the long-term unemployed. The health support workers' role was to provide support to families in various ways such as assistance with shopping, babysitting, or casual visiting. Some study participants expressed unease at working with this group as they feared that the health support workers (HSWs) would experience difficulty in maintaining the boundaries between their various roles such as community member, neighbour or friend, and support worker. Some health visitors described concerns about the HSWs' understanding of professional standards

of confidentiality. Other concerns included the possibility of HSWs having information due to their pre-existing friendships that might influence their judgments, or that would be withheld from health workers. Some participants mentioned their fears that the HSWs did not share the same work ethic as health care workers. This view was disputed by other study participants who felt that the HSWs were in general well trained and professional in their work.

Some participants described a lack of concordance between the aims of Starting Well and the aims of the project partner who provided the HSWs. At times the HSWs were unavailable for service delivery as their education and training took precedence over their service delivery responsibilities. This was attributed to the aim of the partner to retrain and find work for previously unemployed people, rather than provide a health service.

Addressing inequalities

The majority of the study participants identified reducing inequalities as an important part of their work; however, this underlying moral imperative raised ethical issues. Some participants described their concerns that Starting Well was too limited in its objectives related to reducing inequalities, as there were no provisions for questioning the circumstances or origins of disadvantage. They expressed their fear that Starting Well might provide a political solution for ameliorating the effects of severe disadvantage, while remaining silent about the societal inequalities that led to the need for such amelioration in the first place. In effect, Starting Well might be a way of making children better able to cope with situations that should not be permitted to exist at all.

A second set of participants' concerns related to providing the service to those who needed it most. The Starting Well program ran in two areas of Glasgow defined by postcode, and selected because of their levels of disadvantage. Within these deprived areas, there was heterogeneity, so that some families receiving the service were less needy than other families who were ineligible for the service as they lived outside the project boundaries. At a population level, the intervention targeted inequalities, but this was at the cost of sometimes increasing inequalities for individual families. This was described as unfair by some

study participants who had worked across the boundaries and who knew equally disadvantaged families that were excluded from the project.

Study participants were committed to Starting Well and felt that it would make a difference, but indicated it would not be sustainable to offer this level of service across the whole of Scotland, and there would need to be some targeting of services. Participants described mixed feelings about targeting. Some participants agreed with the decision of the Starting Well steering committee to target vulnerable communities rather than vulnerable individuals, in part to avoid stigmatisation of individual families. This agreement was qualified by the observation that the intensive visiting and close relationships formed by the visiting staff had led to the identification of previously undocumented problems, especially gender-based violence and sexual abuse. Participants were concerned that these discoveries might lead to stigmatisation of these communities, just because their problems had been identified. In addition, some participants felt helpless at the lack of services to address these newly identified needs, and some described it as unethical to identify severe needs but not provide services to address these.

Discussion

This original study systematically documented ethical issues identified by public health professionals in a child health home visiting program. To date there is little existing literature reporting the results of qualitative investigations of ethical issues in public health. This study supports the view that competing values and obligations are central issues in public health ethics (Weed & McKeown, 2003). There is an irreducible tension between providing services and the other demands faced by practitioners, including evaluation. As some of the participants in this study described, evaluation can seem irrelevant to the job at hand or even a hindrance to providing good clinical care. These tensions were described as ethical, but may be amenable to practical solutions. The experiences of practitioners should be an integral part of developing the evaluation of programs, and, in turn, evaluations should be flexible enough to accommodate a wide range of findings in practice. Such an approach would lead to benefits in terms of better informed (and so hopefully more accurate) data collection by

practitioners, and evaluations that better capture actual practice.

Targets serve both evaluation and political needs; those funding expensive health interventions require targets to demonstrate benefits. Despite their necessity, targets have the potential to skew practice and to encourage paternalism and coercion. One of the fundamental ethical tenets of health care is that the practitioner will act for the good of the client or patient. The introduction of targets linked to the ongoing funding of programs means that practitioners have another reason to act, related to the service rather than to the good of the client. Participants in this study did not report coercing clients to meet targets; however, some recognised the potential for this to happen and elsewhere public health practitioners have described that meeting targets can compromise client autonomy (Rogers, 2004a).

Starting Well is an example of a primary health care initiative aimed at providing health care and preventive activities for a population known to be at risk due to socioeconomic disadvantage. This can be grounded in an ethical commitment to reducing health inequalities related to disadvantage. In turn, this ethical commitment is justified by beliefs that such inequalities are wrong because they are undeserved, affect people's other opportunities in life and are avoidable (Brock, 2002). Against this background, staff working in Starting Well identified a number of ethical tensions inherent in the very task of reducing inequalities. This finding highlights the ethical "gap" that can occur between intentions and consequences, reminding us that neither alone is sufficient for a full ethical account. Traditionally, consequences have been the public health ethical yardstick. This is now being challenged in various ways, with accounts of virtue-based, rights-based and communitarian public health ethics (Mann, 1997; Mooney 1998; Horner 2000; Rogers 2004b). One of the main criticisms of consequentialism is that the focus on aggregate benefits and harms can lead to a certain disregard for their distribution, making it a blunt tool for addressing inequalities (Brock, 2002). In Starting Well, the choice of the two intervention sites was driven by the need to achieve the greatest good with the available resources, but, as some participants noted, this was at the cost of increased inejmiqualities for some individual families. It is not clear that it would be possible to eliminate these kinds of inequalities in the context of a demonstration project in which there is an imperative to provide evidence about the effects of intensive home visiting prior to any national introduction. As with clinical research, the benefits and burdens are not always fairly distributed, but this may be ethically tolerable if there is a commitment to making any benefits available to the wider population once the trial period is completed.

More troubling was the observation by participants that Starting Well may simply make individuals better able to adapt to or survive their disadvantage. This raises questions about the scope and role of health interventions in relation to health inequalities. If poverty and social alienation are major risk factors for ill health and subsequent health inequalities, it is not clear that any amount of home visiting will alter this in a meaningful way. If Starting Well is successful in improving health outcomes for this disadvantaged group, this finding may in fact divert attention away from the root causes of health inequalities towards simply reducing their effects. Whitehead, Dahlgren, & Wilson (2001) have argued strongly that policy should describe, analyse and address root causes of health inequalities, as well as reduce their consequences; by their criteria, Starting Well is clearly only part of any comprehensive policy response to health inequalities.

Do health departments have a responsibility to address root causes of health inequalities, or is this beyond their scope? Ideally, addressing inequalities should be a whole-of-government policy as there is a danger that if health departments are left with the sole responsibility, it will be very difficult to make meaningful changes in, for example, opportunities for education or employment. Currently there is a danger that other government departments see health inequalities as solely under the jurisdiction of health departments, thereby missing opportunities to address root causes. This creates a moral responsibility for health departments not only to provide services that will improve health outcomes for the disadvantaged, but also to lobby for interventions that do address root causes. Part of this responsibility should include a requirement for health equity impact assessments on all new government programs, irrespective of their department of origin.

This study has some limitations. Due to concerns about confidentiality, interviews were not taped,

and it is possible that important material was omitted in the note-taking process. The sampling strategy aimed for breadth of professional roles; this meant that differences between professional groups (such as health visitors and management staff), could not be explored in depth. Analysis was performed by the author alone so that this necessarily reflects her own preconceptions about public health ethics. Generalisability is limited because of these factors. However, presentation of results to relevant public health audiences (including study participants) has met with endorsement as to the nature and importance of the problems identified. Finally, this study describes the views of public health practitioners about the ethical issues raised by Starting Well. A full account of these issues also requires the views of the families involved. Families have been interviewed in the as yet unpublished evaluation of Starting Well (Public Health Institute of Scotland, n.d.); to my knowledge there was no explicit focus on ethical issues in the evaluation, making this an area for future study.

Conclusion

This study shows that there are ethical challenges raised by interventions to reduce inequalities in health. We need the kind of evidence that Starting Well produced, to guide policy and practice in reducing health inequalities, but in seeking evidence, we must be aware of the conflicting responsibilities faced by practitioners and the sometimes paradoxical effects of our actions despite ethical intentions. There is a need for explicit ethical evaluations of both public health policies and programs. The former may occur in a de facto way when health care priorities are determined, but opening up decision-making to ethical scrutiny will provide a more rigorous way of evaluating competing claims. These theoretical evaluations should be supplemented by empirical work detailing the ethical issues encountered in the implementation of projects, by those receiving as well as providing services. Such a cycle of ethical evaluation will contribute to greater clarity about the ethical foundations and consequences of public health activities.

Finally, we must recognise that public health is inescapably political, creating the imperative for health workers to be political advocates, to constantly remind the politicians and public alike that the answers to health inequalities lie in large part outside the health arena.

1   Carstairs deprivation score is an area-based measure, calculated at postcode sector level (e.g. EH3 5) and is derived from four census variables: overcrowding, male unemployment, social class and car ownership. These items are combined to create a composite score. Deprivation quintiles use the composite score to derive five equal size population groupings from less deprived (dep quin 1) to more deprived (dep quin 5).

References

Brock, D. (2002). Priority to the worse off in health-care resource prioritization. In R. Rhodes, M. Battin, & A. Silvers. (Eds). *Medicine and Social Justice: Essays on the distribution of health care* (pp. 362-372). New York: Oxford University Press.

Brown, U., Scott, G., Mooney, G., & Duncan B. (Eds.). (2002) *Poverty in Scotland 2002: People, places and policies (4th ed.).* CPAG, in association with Scottish Poverty Information Unit.

Child Health Surveillance Programme. (2004). Information and Statistics Division. Retrieved 1 June, 2004, from http://www.isdscotland.org/isd/info3.jsp?pContentID=930&p_applic=CCC&p_service=Content.show&

Elkan, R., Kendrick, D., Hewitt, M., Robinson, J A., Tolley, K., & Blair, M., et al. (2000). The effectiveness of domiciliary health visiting: a systematic review of international studies and a selective review of the British literature. *Health Technology Assessment, 4*(13).

Horner, J.S. (2000). For debate: the virtuous public health physician. *Journal of Public Health Medicine, 22,* 48-53.

Information and Statistical Division, Scotland. (2002). *Breastfeeding by Deprivation and Maternal Age.* Retrieved 1 June, 2004, from http://www.isdscotland.org/isd/info3.jsp?pContentID=2022&p_applic=CCC&p_service=Content.show&

Information and Statistical Division, Scotland. (2003a). *Mortality by deprivation quintile and age.* Retrieved 1 June, 2004, from http://www.isdscotland.org/isd/info3.jsp?pContentID=2552&p_applic=CCC&p_service=Content.show&

Information and Statistical Division, Scotland. (2003b). *Emergency admissions for RTA for children under the age of 15, by deprivation category, year ending March 2002*. Retrieved 1 June, 2004, from http://www.isdscotland.org/isd/info3. jsp?pContentID=2231&p_applic=CCC&p_ervice=Content.show&

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *Lancet, 358*, 483-88.

Mann, J.M. (1997). Medicine and public health, ethics and human rights. *Hastings Center Report, 27*, 6-13.

Mooney, G. (1998). "Communitarian claims" as an ethical basis for allocating health care resources. *Social Science & Medicine, 47*, 171-1180.

Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care. *British Medical Journal, 320*, 114-6.

Public Health Institute of Scotland. (n.d). Starting Well Demonstration Project information page. Retrieved 5 September, 2004, from http://www.phis.org.uk/p rojects/default.asp?p=FAC

Rogers, W.A. (2004a). Ethical issues in public health: a qualitative study of public health practice in Scotland. *Journal of Epidemiology and Community Health, 58*, 446-450.

Rogers, W.A. (2004b). Virtue ethics and public health: a practice-based analysis. *Monash Review of Bioethics, 23*, 10-21.

Spurrier, N.J., Sawyer, M.G., Clark, J.J., & Baghurst, P. (2003). Socio-economic differentials in the health-related quality of life of Australian children: results of a national study. *Australian & New Zealand Journal of Public Health, 27*, 27-33.

Starting Well. (n.d.). Project website. Retrieved 1 June, 2004, from http://www.gorbalslive.org.uk/data/community/cgroups/ startingwell.htm

The Scottish Office. (1999). *Towards a Healthier Scotland - A White Paper on Health*. The Stationary Office. Retrieved 1 June, 2004, from http://www.scotland.gov.uk/library/documents-w7/tahs-00.htm

Weed, D.L., & McKeown, R.E. (2003). Science, ethics and professional public health practice. *Journal of Epidemiology and Community Health, 57*, 4-5.

Whitehead, M., Dahlgren, G., & Gilson, L. (2001). Developing the policy response to inequities in health: a global perspective. In T. Evans, M. Whitehead, F. Diderichsen, A. Bhuiya, and M. Wirth, M. (Eds.), *Challenging inequities in health: from ethics to action* (pp 308-324). New York: Oxford University Press.

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