Exploring the Perceptions of Young People in Care and Care Leavers of their Health Needs

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Introduction

The health of young people in public care has received increased attention at a political and practice level in recent years. The introduction of national care standards (Scottish Executive 2002) in areas relating to health by the newly formed Scottish Commission for the Regulation of Care ('the Care Commission') is a welcome development. These standards, it is hoped, will significantly contribute to the improvement of young people's health whilst being looked after away from home.

A growing body of research is contributing to understanding the particular health issues and needs of children and young people whilst looked after away from home. However, there is still little known about young people's perspectives. The research discussed in this paper contributes towards understanding health as it applies to a disadvantaged and vulnerable group of young people from a young person's perspective.

This paper presents findings from a research study into the health needs and concerns of young people in care and leaving care (aged 14 to 24 years) carried out in Glasgow during 2001 (Scottish Health Feedback 2001). The study was commissioned by the Glasgow Alliance Care Leavers Social Inclusion Partnership (known as *the big step*), which was set up in 1999 as part of the Scottish Executive's Social Inclusion Strategy. The paper discusses the findings and draws implications for future policy and practice.

Background to the research

Young people looked after away from home are particularly vulnerable to systematic and personal barriers to good health. Some authors have gone so far as to suggest that they constitute some of the most vulnerable young people in society (Brodie et al, 1997; Audit Commission, 1994). Their health status is influenced by a range of factors relating to their social and family backgrounds and by the very nature of being in and moving from care. The transient and disruptive nature of being in care, being separated from parental care and

support, coupled with irregular school attendance, often results in young people missing the continuity in health care and health education that other young people would encounter.

The basic health care needs of young people who are looked after are consistently not met (Butler and Payne, 1997). Many experience periods of isolation from friends and peers, low self-esteem, poor life and social skills, as well as a background of distressing life experiences. Moreover, the health of young people in care is often poor in comparison with that of their peers, with higher levels of at-risk behaviours such as drug taking, higher rates of teenage pregnancy and a much greater prevalence of mental health problems (Howell, 2001). As Butler and Payne (1997) argued, the worrying issue for corporate parents is the evidence that being 'in care' can exacerbate existing problems and even introduce new hazards.

The *big step* Social Inclusion Partnership (SIP), and the health research reported in this article, focuses on young people who were in different stages of moving on from local authority care to independence. While independent living for most young people is a daunting prospect, for young people leaving care it is often more difficult, as they are less likely than their peers to be adequately prepared, resourced and equipped for such a transition. Research also indicates that they often have to make the transition to independence up to six years sooner than the median age of other young people leaving the parental home (Biehal et al., 1995).

A recent study of throughcare and aftercare services in Scotland (Dixon and Stein, 2002) found that the mean age for young people leaving care was 16 years and the majority (94 per cent) had legally left the care system by the age of eighteen. Furthermore, the study reported that a majority of young people (61 per cent) had received no planned programme of preparation for leaving care. Many of these young people will also experience social isolation and exclusion as they are less likely than their peers to have access to social support, family and community resources and networks if and when they meet social, health and emotional problems. All of these factors are considered to be particularly detrimental to good health and well-being and highlight the need for adequate throughcare and aftercare services for young people looked after away from home.

Research design and methods

The main purpose of this study was to investigate, at a local level, the health views and needs of young people in care and leaving care, to inform the planning and delivery of appropriate and relevant services and information for young people.

Studies have shown that young people are the most appropriate informants about their perspectives on health and asking their opinions can yield rich data (Ireland and Holloway, 1996). Young people's access to health services generally and the importance of involvement in health have received increased policy attention (NHS Scotland, 2002; Scottish Executive and Fast Forward, 2000). In this research, both quantitative and qualitative methods were used to explore young people's perspectives.

The study was carried out in two distinct phases. Phase one involved a questionnaire survey, during January 2001, of young people (aged 14-24 years) living in young people's units or residential schools, as well as those who had left care. During the second phase, the focus groups were used to explore some of the issues from the questionnaire in greater depths.

Questionnaire

The West of Scotland 11 to 16 Study established the self-completion questionnaire as an effective data-gathering tool about the health of young people (Young et al., 2000; West and Sweeting, 1996). However, the target population for this research was to be approached in much less controlled circumstances. The key issue was to design a questionnaire that was 'user-friendly', while still aiming to gather meaningful data for planners. Researchers worked closely with relevant staff in Social Work and *the big step* to ensure young people received support and encouragement to complete the questionnaire and financial incentives were provided.

The questionnaire included two standardised measures. The first was a 10-item Depression Scale (Kandel and Davies, 1982), used in the 11-16 Study with Scottish teenagers (Sweeting and West, 2000). Although this should not be taken to measure specific, diagnosable, mental health problems, it is generally taken as a reliable indicator of mental distress. The second measure was an adapted Rosenberg (1965) scale as used in the 11-16 Study to provide a proxy measure of self-esteem. Other questions aimed to gather young people's opinions about health, their lifestyles and health behaviours, their use of and attitudes towards health services and to establish what health information and advice would be useful to them.

The questionnaire was distributed among 116 young people aged 14 years and up, who had experienced, or would soon experience, the transition to independent living. This included 86 young people living in residential care (young people's units and residential schools) and 30 known to Leaving Care Services (LCS) living in supported and independent tenancies, with supported carers, and in hostels. The sample was stratified for gender and age across the selected residential units and schools, while the sample from LCS were selected pragmatically on the basis that they had a support worker.

Focus groups

Despite organising groups in accordance with known best practice guidelines with children and young people (Greenbaum, 1987 cited in Hill et al., 1996), including having both single sex groups of 'younger' teenagers and mixed sex groups of 'older' teenagers, and offering incentives, the focus group method was not as successful as hoped. Just fourteen individuals participated, even though 35 questionnaire respondents had initially indicated a willingness to take part. Even so, the method did achieve the involvement of individuals who did not usually get involved in planning and extended the range of views offered to *the big step*.

Profile of the young people

Ninety-six of the 116 young people approached returned the questionnaire, a response rate of 87 per cent. Fourteen of the 96 took part in focus groups to further explore issues and themes from the questionnaire. Almost equal numbers of males and females responded (53 per cent and 47 per cent respectively). They varied in age from 14 years through to 24 years, the most common age being 15 years (26 per cent).

The majority (66 per cent) were living in young people's units or residential schools, which is not surprising given how the sample had been drawn. Respondents were predominantly from one of three types of accommodation: young people's units (29 per cent); residential schools (27 per cent) or supported tenancies (21 per cent). Typically, they had been in their current placement under a year, even though they had commonly been in care for more than three years.

Findings

Views of current placement

Over half (54 per cent) were either happy or very happy with their placement. Most positive were those living in supported tenancies and least positive were those living in residential settings. Just under a fifth (17 per cent) were dissatisfied with where they were living, and more than half of these were living either in a residential school or young people's unit. For those in residential care, the critical success factor was the quality of relationship with staff as well as with other residents. Views ranged from staff being described as 'supportive' to 'staff can do your head in'.

There were, nevertheless, contrasting views about life in residential care settings. While ten young people were 'unhappy' with either the residential unit or school, an equal number were 'very happy' with the placement. A further third, were neither 'happy' nor 'unhappy'. The experience of being separated from family

and what they perceived as 'poor links' with their natural family were significant determinants of satisfaction or dissatisfaction. They often complained of hardly seeing, or of missing family and friends.

Understanding of 'health'

'Health' was not a concept that young people in the survey easily related to. They defined being healthy in terms of physical fitness or as the absence of disease or illness. Although staying fit and healthy was important for a minority of respondents, the almost universal view was typified by one respondent who commented, 'health means nothing to me, can't relate to it'. This supports other research findings that young people generally do not perceive health as a major life concern in the same way most adults perceive their health status (Shucksmith et al., 1997). Despite this, the majority perceived themselves as 'healthy and fit': four out of five stated they were 'quite healthy' or 'very healthy', and only 22 per cent considered themselves as 'unfit'.

Health inequalities

The survey showed evidence of health inequalities and unhealthy lifestyles and behaviours among young people leaving care. It found significantly high levels of depressive mood and low self-esteem, as well as deliberate self-harm (45 per cent had self-harmed). It is recognised that young people use self-injury as a way of dealing with difficult feelings and as a way of feeling more in control (Royal College of Psychiatrists, 2002). We may therefore conclude that many young people answering this survey were struggling to cope with their situations and had found alternative solutions to dealing with their particular feelings and pressures.

In addition there were high levels of smoking (75 per cent were smokers); drinking to excess (14 per cent stated they were drunk most days); drug taking (84 per cent had used cannabis at least once and 60 per cent had tried ecstasy at least once); poor diet (around one third did not eat any fruit or vegetables); and low levels of physical activity (over a third never took part in any exercise or sports).

Using the same cut off point as other studies (scores of 21.7 or more), the incidence of depressive illness was far higher than in other clinical samples of depressive mood in adolescent populations (Kandel and Davies, 1982). Overall, 28 per cent were found to be highly depressed compared to 18 per cent of the American teenagers. More females (33 per cent) than males (23 per cent) were highly depressed or at risk for diagnosis of major depressive illness; many of these were living in residential care settings. There was a link between self-injurious behaviour and high scores on the depression scale in 37 per cent of cases.

When compared with other teenage populations, the young people in this survey showed evidence of low self esteem: only 25 per cent of respondents scored 20 or more on the adapted Rosenberg scale compared to 56 per cent of teenagers in the 11-16 Study (Young et al., 2000). The average score for both males and females was between 15 and 19. Females tended to have the lowest scores, especially those under 16 years. Again, there was a close relationship between self-harm and low self-esteem: 85 per cent of those who self-harmed had self esteem scores below 20.

Barriers to healthy lifestyles

There was little evidence of a positive culture within care that emphasises health, in its widest sense, as a priority issue. Young people believed that being in care, especially residential care, was a barrier to a healthy lifestyle. They suggested that residential staff did not take incidents of drug taking, smoking and drinking seriously enough, and wanted staff to exert more adult control and to 'teach people to be social drinkers' or 'not to drink at all'.

Worthy of mention is the finding that up to a third of young people had only started smoking (27 per cent), or taking drugs (31 per cent), or drinking alcohol (29 per cent) while in care. As the most frequent reasons teenagers give for having tried their first cigarette is 'to see what it was like' and peer pressure (Sweeting and West, 2000), such findings should be a cause for unease.

Young people commented that they smoked, took drugs and drank alcohol because they were 'stressed out in care', or to 'take the bad things away'. Kandel and Davies (1982) established a link between depressive mood and illicit drug use other than cannabis and suggested that some adolescents might use drugs as self-medication to relieve their depressed state. Young people in this study spoke about using substances less as a social activity, and more to 'forget the bad things'. Others talked about drink and drugs giving them self-confidence and helping them to relax.

Some felt they had been more physically active before they came into care and they wanted to be more active. Barriers to becoming more physically active included not having enough money to meet the costs of some sports or exercise and a lack of personal motivation and encouragement:

> *We're always too busy or there's not enough staff on, or other people misbehave and then they don't let other people go (female, 14 years)*

Impact of leaving care

The most pressing health issue for young people was how the move from care to independent living would affect their health. As with the Save the

Children Fund research (1995), the study found that young people perceived the transition from local authority care as having a negative impact on health. They wanted more information on all aspects of independent living, as one stated, 'to stand on my own two feet'. Young people commented that poor preparation for leaving care was resulting in ill health, in young people becoming homeless, getting into debt, eating a poor diet, and becoming socially isolated and excluded.

Accessing health services

Apart from visiting a GP, respondents' use of health services was rare. This is perhaps predictable when most respondents considered themselves as healthy and fit and perceived health services as the place to turn 'only when you're ill'. This mirrors the findings of Mather et al (1997). Apart from seeing their GP, few had made use of any health services, apart from high numbers of young people accessing accident and emergency departments (46 per cent in the previous 6 months). This might have been because young people found such services more approachable or easier to use than primary health care services, or it might more reflect the high 'risk taking' behaviours in relation to drugs and alcohol. Those in contact with family planning or contraceptive services within the past year were in the minority (just 28 per cent of respondents), and two out of five respondents did not know where the nearest young people's sexual health or contraception service was.

Positive aspirations

In contrast to the survey's findings regarding depression and self-esteem, the majority of respondents were perhaps surprisingly positive about their future prospects. Most young people thought that by the age of 22 they would have a job (81 per cent), they would be in good health (68 per cent), they would own a car (60 per cent), and they would be a student at university or college (50 per cent). Available research which demonstrates the poor outcomes for young people in these areas (Dixon and Stein 2002, *the big step* 2002) would suggest that there is a significant gap between young people's hopes and aspirations for the future and the success of services in enabling them to achieve these. This represents a challenge for services concerned with improving outcomes for young people leaving care.

The Way Forward

The research was designed to provide useful information for multi-agency strategic planning. Aptly, the research was driven by a multi-disciplinary health interest partnership from the start. As emphasised by recently published guidance for the promotion of health for looked after children in England (Department of Health, 2003), this approach was taken to ensure that services

would ultimately be better co-ordinated and managed at a strategic level, and that more holistic and sensitive services to children and young people would be available at an individual level.

This research highlighted a number of issues in relation to promoting better health among looked after young people, which are being acted upon locally. That young people did not relate to health as an issue and rarely used health services suggests that the most effective approaches to tackling the behaviours and lifestyle issues revealed in this survey would not be through traditional health services alone. The findings also suggest that the most useful starting point for interventions would be building young people's self-esteem and self-confidence and adopting an holistic approach to health.

It is not simply a matter of providing health education, advice or information, or of awareness-raising, but of addressing the underlying psychosocial causes for poor motivation and unhealthy lifestyles. Work involving young people in health (Scottish Executive and Fast Forward, 2000) emphasises the importance of capitalising on young people's interests. For example, to tackle some of the health issues raised it might be more effective to organise music or dance events or set up a football team, than to set up groups specifically to look at healthy eating or the importance of exercise to health.

The respondents in this survey showed that young people can make interesting and valid contributions to discussing issues around health, and that intentional ways need to be found better to engage them in exploring this. While the emphasis of recent government policy has been to encourage services to promote health and well-being and not to focus solely on the detection of ill health; there was evidence from this research that young care leavers were disempowered in terms of taking responsibility for their own health. This could be changed through promoting their active involvement in defining and addressing some, or all, of the health problems and concerns raised by this research in ways that are relevant to their lives, and in partnership with the staff who support them.

A third issue was that to address the health of young care leavers, their concerns around the transition to independent living and how this impacts on their health need to be tackled directly. The respondents highlighted both that there were aspects of being in care, and in particular residential care, that appeared to militate against developing healthier lifestyles. Further, there was a wish for adults to exert more 'control' over negative health behaviours, such as high alcohol consumption or taking illicit drugs, as a demonstration of care. Although health information and advice was available to most young people in care, this fell far short of respondents' expectations.

A range of specific health concerns was highlighted that require to be addressed

by multi-agency partnerships. Tackling the structural and other barriers to health identified by the survey, for example the lack of money, poor motivation and lack of opportunity to access physical activities, will demand new approaches and the need for multi-agency partnerships, perhaps within the context of *Health for All* alliances and Community Health and Community Planning Partnerships (Scottish Executive 2003), and collaborative working both between different agencies and between departments within the same local authority.

Conclusion

Despite a recent focus on the health of looked after young people in policy and practice, the findings reported here show that there is little room for complacency, and suggest a pressing need actively to engage young people in defining their own health and addressing the health problems they face. In particular, attention needs to be directed at the process of leaving care and the support provided. Furthermore, the issues raised in relation to residential care, including a disproportionate number of young people in these settings suffering low self-esteem, who had deliberately self-harmed, and who had high levels of depressive mood, should be investigated further.

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