Managing the care journey

Meeting the health care needs of children in out-of-home care

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This paper looks at the issues impacting on the physical and mental health of children placed in out-of-home care and at the capacity of the care system to recognise and respond to those needs. It draws on the findings of a recent exploratory research project in Perth, commissioned by the General Practitioners' Evaluation Programme (GPEP), in which the author participated as a researcher. The paper focuses in particular on the paucity of information about the child's journey through the care system, reflecting on the aggregate 'snap-shot' focus on cohorts and 'children as through-puts', rather than on individualised, longitudinal profiles of placed children. A typology of care journeys is presented as a potential framework for locating and mapping children's experiences.

I would like to acknowledge the opportunity to participate in the research undertaken by Underwood et al. This project assisted me to crystallise some concerns long held as a practitioner in out-of-home care, and enabled me to develop the typology presented in this paper.

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In 1999, a small, exploratory study was undertaken into the provision of General Practitioner Services to children in out-of-home-care in Perth, Western Australia (Underwood et al 2000). This paper focuses on one aspect of the Perth study: an exploration of the health care needs of this population of children and the adequacy of service provision as perceived by 'welfare professionals'. In particular, it considers the 'care journeys' of children in the care system and the implications for care providers seeking to plan for and respond to their physical and emotional health.

METHODOLOGY

The research design for the study was exploratory (Denzin & Lincoln 1998; Guba & Lincoln 1998), the intention being to discover the views of those professionals whose responsibility it is to respond to and meet the health needs of children in State care. The study adopted a multi-method research design, and a mixture of representative, opportunity and snowballing sampling was utilised in order to maximise the richness of the data provided. Thirty-eight people were interviewed, half of whom were carers, and half social workers in co-ordinating/decision-making roles in government or non-government agencies. Interviews were loosely structured around two key themes:

1. health issues for children in out-of-home-care;
2. the systemic factors impinging on the provision of appropriate health care to children in care.

WHAT THE LITERATURE TELLS US

The project included a review of recent research in the United Kingdom and North America. The Western Australian outcomes are consistent with these studies, highlighting the transience, disruption and loss of history faced by children placed in out-of-home care, and the resulting difficulties in adequately meeting their physical and emotional health needs.

The research literature indicates that, despite differences in both the health and welfare systems in the UK and North America, their populations of children in care are from similarly deprived sectors of the community. It indicates also that neither system adequately meets the health care requirements of children in out-of-home care. These findings are supported by the limited body of Australian research (Cavanagh 1992; Scott & O'Neil 1996), and also substantially supported by anecdotal information in Western Australia.

The UK research highlights the disruption and loss of history faced by children placed in the care of local authorities. It reports the ineffective and/or negative and damaging impact on children and their families as a consequence of the lack of proactive, co-ordinated and holistic planning and of an absence of intra- and inter-agency clarity about roles and responsibilities. It indicates that the focus of much intervention appears to be on events, symptoms and behaviour rather than on underlying causes of difficulties or on the whole child in context. It notes also that, once a child is placed away from home, there is a lack of continuity of care and a failure in liaison between the various adults and agencies charged with the care of the child (DHSS 1985; BAAF 1998; Bamford & Wolkind 1988; Beal et al. 1985; DoH 1991a; Doorbar, Lewington & Unwin 1995; Hendricks 1989; Mostyn 1997; Parker et al. 1991; Payne 1995; Short 1984).

Much of the American social work literature on children in out-of-home care is at the 'broad-brush', macro level, with little specific information about health care issues. However, within the medical profession, there has been a growing interest in the provision of health care and medical services for children in foster care (Blatt et al. 1997; Carlson 1996; Chernoff et al. 1994; Halfon, Mendonca & Berkowitz 1995; Hochstadt et al. 1987; Jaudes et al. Undated; Simms 1988; Simms & Halfon 1994; Szilagyi 1998). A number of medical schools and schools of paediatrics have considered the identification of and response to the health requirements of children and young people entering out-of-home care. These studies confirm the findings of the UK research, reporting a high prevalence of physical and mental health problems and of developmental delay amongst children in the care system, and an unco-ordinated and inadequate response by caring agencies. They indicate also that there is an over-emphasis on children in long-term care, rather than an early consideration of the care needs of children at the point of admission.

The 1989 Children Act (UK), which was significantly influenced by research completed in the 1980s, emphasises the responsibility of the state as 'corporate parent' to safeguard and promote the health and general wellbeing of the child in care. However, more recent UK studies report that, despite this stated emphasis, there is a continuing lack of awareness of, or a co-ordinated response to, the health needs of the 'looked after'[1] population (Broad 1999; Butler & Payne 1999; DoH 2000; DoH 1999; Hill 1999; Marmot & Wilkinson 1999; Mather, Batty & Payne 2000; McCann et al. 1998). Butler and Payne report that research findings suggest that:

> the passage of the burden of health care from parents to other carers may result in the loss of both factual and intuitive knowledge derived from the parents' previous daily and intimate contact with the child. The knowledge lost is not only that of the child's normal state of health and the minor daily signals whereby a parent is sensitive to any changes in the child's health, but also that of her or his health history (Butler & Payne 1999:288).

In one of the few Australian studies that considers the impact of placement on the health of children, Scott and O'Neil (1996) argue that while the community has become far more aware of the problem of child abuse, it has a long way to go in developing effective responses to the problem and they identify the 'inherent dangers of placements' stating that:

> the sadness and anger expressed by many children in care are as much a product of their separation as of the reason for their being in care ... To be raised outside the acceptable 'family' model is a heavy burden carried by these children. Secondary abuse, through lack of identity, lack of belonging and, on occasions, exposure to similar risks that brought them into placement, has a significant disempowering impact (Scott & O'Neil 1996:52).

They conclude that placement is 'a psychologically hazardous' way to ensure a child's safety.

RESEARCH FINDINGS

HEALTH DIFFICULTIES

Physical health

The welfare professionals participating in the Perth study identified the same range of conditions and symptoms as those outlined in the research literature. Carers of younger children reported a common pattern of poor nutrition and an absence of routine, as well as evidence of general neglect when children are placed. This pattern accords with the findings of Jaudes et al (undated) in the United States and Simms and Halfon (1988; 1994) in the UK. Carers reported also that they are often required to deal with medical conditions that have not been addressed adequately by the children's parents. In line with recent studies (Broad 1999; DoH 2000; DoH 1999; Ward 1995), participants also reflected on the difficulty frequently experienced in obtaining a child's health history, either from family or from within the health or welfare systems. The absence of such a history places children at significant risk of missing 'routine' health measures such as immunisations and dental and optical tests. On occasions, it also denies children continuity of care for more acute conditions such as respiratory tract infections, resulting, as the literature and the Western Australian study indicate, in a widespread prevalence of chronic ear disorders. One worker described the placement process as follows:

> Necessary health information is frequently unavailable at the critical point of placement, a fact which is of itself an additional risk associated with the placement process ... They may need medical attention constantly in the first week of placement — some of which may reflect the stress of placement — but without history you can't say. This information about reactions to placement may also not be seen as significant and documented and handed on so you have to start again each time. So history is not maintained on placement. The carer or officer may not think a reaction is worth reporting, and if the placement is once-off it may not be, but often these children are re-entering the system at intervals and that information is really important.

Carers noted also a general lack of self-care and a significant lack of a sense of positive identity and self worth, and an absence of 'life energy' amongst children, particularly adolescents. Once again, these comments confirm the findings in the research on psycho-social wellbeing of the care population (DoH 2000; Marmot & Wilkinson 1999; Mather, Batty & Payne 2000; Mather, Humphrey & Robson 1999) which point to an absence of appropriate health education both at home and through the school system, within which many older children in out-of-home care are highly

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[1] This term applies to children in care in the UK, for whom the State has assumed parenting responsibility. The equivalent group in Western Australia are Wards of the State.

marginalised. Indeed, there was a consensus of opinion amongst all participants that the physical health of children and young people, although less than optimum, is less an issue of concern than their psychological and mental health.

Psychological health

All participants raised significant concerns about the psychological wellbeing of looked after children, and reported their awareness of the general tendency to focus on the child's behaviour as a problem rather than as a symptom of the social and psychological pressures with which they are faced – in their families and in care. This difficulty is compounded by the tendency noted by several participants for children's behaviour to be 'over-medicalised' prior to placement. The very high prevalence of Attention Deficit Disorder (ADD) and Attention Deficit and Hyperactivity Disorder (ADHD) amongst the population of children in care was cited as an example of this problem. One worker commented:

> ADD used to be mental health, now you wouldn't get a referral that hasn't got ADD in it somewhere.

One of the difficulties posed for carers of children and young people diagnosed with ADD or ADHD is that, frequently, the child's view of their behaviour has become so medicalised that they have not developed any inner-directed control mechanisms. Instead, many become entirely externally controlled and they blame their inappropriate behaviour on their medication and/or their 'illness'. Those working with older children identified this issue as a major concern.

Other psycho-social conditions and mental health problems identified by professionals and carers working with older children and adolescents are as follows:

- self harm and unsafe practices such as early use of cigarettes and alcohol and early sexual activity (a problem noted particularly amongst girls);
- a tendency to 'live for the moment' and an absence of a sense of past or future;
- substance abuse;
- depression;
- eating disorders;
- a generally poor level of self care;
- a sense of stigma and 'difference';
- a level of anger and social alienation which results in anti-social behaviour leading to a label of 'oppositional/defiant'.

These problems accord very closely with those identified in the UK and American research (Broad 1999; Chernoff et al. 1994; DoH 1999; Halfon, Mendonca & Berkowitz 1995; Hendricks 1989; Mather, Humphrey & Robson 1999; Pinkney 1994). Participants all noted that the care experience, which is one of transience, fluidity and unpredictability for many children and young people compounds emotional and psychological difficulties.

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SYSTEMIC DIFFICULTIES

Transience and uncertainty

A key systemic problem identified by all participants in the study is that of transience and uncertainty, mirroring the concerns identified in the UK research (DoH 1998; DoH 1999; Doorbar, Lewington & Unwin 1995; Mather, Batty & Payne 2000; Mather, Humphrey & Robson 1999). In the Perth study, this transience is endemic. Children frequently move from one uncertain and disorganised setting (home) where relationships are fluid and ever changing to another (care) that equals if not increases the unpredictability of their life situation. A carer summed up the situation as follows:

> Transience is part of [the children's] life. It's more fluid than for other children; there is a lack of predictability. It can get quite messy... It's OK as long as they can keep to their routine, but as soon as the routine changes there is a problem, and it frequently shows in their behaviour. Their emotional wellbeing is very up and down depending on what's going on around them.

The uncertainty caused by the transience of the child's living circumstances and the lack of information available at the time of placement is compounded by fluidity and uncertainty at all levels of the care system. Within the statutory placement agency, the social workers responsible for a child's care journey may change frequently because of the recent specialist focus within that organisation, which separates out responsibilities for intake, child protection, supportive and preventive interventions in families. Before becoming the responsibility of an officer with explicit responsibility for planning for his or her care needs, a child may have had several other workers, for many of whom the primary focus would have been on the family rather than the child-in-placement.

The short-term nature of most placements (anecdotal information indicates that only a small percentage of children remain in care for more than four weeks at any one time, although many return for several such placements) means that the majority of children are in care without any 'care plan' at all. As a consequence, significant health conditions may be missed, or, at best, noted and diagnosed but not treated. The structural transience is further compounded at a professional level by the high turnover of staff in many 'caring' agencies. As a result, a child may have several different role relationships in the course of a placement and the people in these roles may also have changed. As one worker stated: 'these children become the only constant in their own lives.'

The lack of consistency in personnel is further compounded by a lack of clarity within and between agencies about the sort of health information that should be obtained for a child, who should assume responsibility for obtaining the information, and who should have access to it. Indeed, a number of participants noted a 'culture of secrecy', and a territoriality that minimises information dissemination. Foster carers noted that they frequently receive little contextual information about a child, despite the fact that they are given de facto parental responsibility.

Referrals to General Practitioners

One of the outcomes of the uncertainty faced by carers seeking to meet the health care needs of the children they look after is a tendency sometimes to refer them to the GP earlier that they believe to be desirable, or than they would feel necessary, had they more information about the child. The need to defend themselves against the possibility of allegations of maltreatment is one reason for these premature referrals. As one social worker reported:

> Carers are at the brunt of so many allegations by parents and children it is inevitable that they will err on the side of caution.

Carers reported that, at times, the GP's lack of sensitivity to their situation was an additional source of stress. Not only are they taking the child to the doctor for an insignificant complaint or injury, they are required also to justify their decision in terms of the child's placement and living circumstances. These tensions about using formal interventions rather than responding spontaneously to a child's needs for health care, and about having to repeatedly 'tell the child's story to strangers', are indicators of one of the major systemically induced health hazards for children in the care system — that they live lives which are much more public than other children's.

Some of this public living is also highly stigmatising and labelling (DoH 1999), as is indicated by the example given by a number of carers who reported the automatic, and publicly stated, assumption that children in their care were responsible for outbreaks of nits at school. Another carer, working with older children, reported the sense of 'difference' and sometimes 'shame' felt by children in her care because of their inability to live 'normally' in a family setting. As one worker commented:

> We expect these children to learn appropriate self-protective behaviours, and yet at the same time we allow them little privacy, and place them in the care of a series of strangers.

The implications of this high visibility for the psychological and emotional health of looked after children are considerable, as noted both in the research literature and in the health concerns identified in this study. A participant commented:

> This group is highly visible in terms of their behaviour, but in the system of health care they are invisible because of the lack of resources in both the welfare and the health system.

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THE PROBLEM OF 'VISIBLE INVISIBILITY': LOOKING AT CAREER PROFILES

As the findings of this study indicate, the out-of-home care system in Western Australia faces the same difficulties as other state authorities in meeting the needs of its care population. Participants were asked for their views on how identified problems might best be addressed. All saw the need for accurate and accessible health information. However, they saw accurate health information as a necessary but not a sufficient response to the problem of providing consistent and appropriate health care for children. As one social worker reported:

> At the moment, issues are not addressed until children get 'to the end of the line' because the issues can't be addressed because they are 'moving through' everywhere else. They are moved on; issues come up again with the next place and they are added to; then it gets too hard and they are moved on again, so the issue gets pushed under the carpet.

This complex pattern of 'visible invisibility' reflects the way in which the career profiles of children in out-of-home care system are recorded, in Western Australia and elsewhere. Categorisations, whether by age, home circumstances or, as in Western Australia, by 'care needs' (Family and Children's Services 1997), fail to make explicit allowance for the variation in 'care careers' of the care population beyond the general recognition of transience and disruption and the broad distinction between short- and long-term care. Children are either 'in-care' or 'not-in-care'.

Much of the literature focuses on the care system in general, or on particular manifestations of the difficulties experienced by children, such as health, educational performance or behaviour. In part, this is a reflection of the difficulty associated with the collection of longitudinal data about children, for practitioners and for researchers. The Department of Health (UK) Report, *Caring for Children Away from Home*, notes (p12) the absence of complete cohorts on which to rely for information and the need for the collection of data from several sources with varying assumptions upon which information is based (DoH 1998). However, the focus of research is on cohorts and categories rather than the career profiles of the children themselves, maintaining the emphasis on *group* visibility and *individual* invisibility.

The importance of preventive, home-based interventions is forcibly argued in the literature (Berg 1994; DoH 1991b; Farmer & Owen 1995; Schuerman, Rzepnicki & Littell 1994; Wilson & James 1997), the goal of these interventions being to prevent or at least to delay admission to care. However, what is insufficiently recognised, in the literature or in practice, is that child placement is frequently an integral part of such intervention. The children placed under these circumstances are frequently 'invisible' to the system and the 'Rule of Optimism' predominates

(Beal et al. 1985), a potentially dangerous pattern of intervention, clearly identified by Reder et al. in relation to child abuse tragedies (Reder, Duncan & Gray 1993). The stories of placed children indicate that this invisibility has the same potential for tragedy within the care system (Owen 1996).

The research notes a particular scarcity of information about the early stages of children's services provision (Chernoff et al. 1994; Mather, Batty & Payne 2000). This lack of information reflects a common tendency for there to be a time lag between placement and planning, leaving placed children in a 'planning limbo'. This problem was noted in the Western Australian study. As one participant observed:

> children are likely to have been in care for some months before they are identified as long-stay. They are likely to have had at least two placements – the average is three. Planning really only *begins* at this point (emphasis in original).

PATHWAYS INTO AND THROUGH CARE: A TYPOLOGY

In order to minimise the likelihood of 'planning blight' for children in care, a clear typology of care career is required. One such typology, developed from the Western Australian study, and through practice experience, is presented below. Four groupings of children have been identified: *passers through*; *repeaters*; *movers* and *stayers*. All four categories were represented in the Perth study.

The passers through

This term refers to children who come into the out-of-home care system for a brief period (two to four weeks on average) in response to an extraordinary event or situation in their family. The family is otherwise able to function as an independent unit but lacks the support system to assist in the care of the children through the temporary crisis. Such provision falls within Hardiker et al's second level of intervention for 'early risk families' (Hardiker, Exton & Barker 1997).

The repeaters

This term refers to those children who experience several periods of short-term care, a group that was highly represented in the study. Typically they are pre- or primary-school children who are placed in foster care at times of family crisis (Kagan & Schlosberg 1989) and/or when the risk to the child appears to be escalating to an unacceptable level. Such placements are usually unplanned, and children are less likely to return to their previous carers than to be placed with a different family each time they come into care.

Above all, participants noted the need for a consistent, caring adult able to 'hold' the child's history, from the first time of placement, and to ensure the coherence of their life-story, emphasising the intricate linkages between a clear, positive sense of self, past and future, physical and mental health and behaviour.

Although some, at least, of these children are looked after for protective reasons, this aspect of placement appears to be minimised, and the stated reason for placement is frequently respite care. The aim of such placements appears to be that of family (parental) support and maintenance, and anecdotal information indicates that the placement of the child is the primary mode of intervention in many such families. This pattern is confirmed in the *Inquiry into the Practice and Provision of Substitute Care in New South Wales* (CSC 2000) which notes that, at 30 June 1999, 53.3% of children in care (4,290) were placed to support the child and/or family through crisis and that 45% of admissions related to their carer being unable to care without periodic relief (CSC 2000:105).

This approach to working with families reflects a current dominant idea in child and family welfare policy and practice of supporting and maintaining families (Berg 1994; DoH, 1995b). Ironically, however, the practice utilises placement as a means of preventing separation, and there is some evidence to indicate that, over time, the frequency and length of placements increase until the child's time in care equals if not exceeds his/her time at home. Given the evidence linking physical and psychological health to the quality of attachment (Feeney 2000), early interventions that rely on repeated respite care potentially increase rather than reduce the likelihood of later long-term placements for children for two reasons:

- attachment patterns are disrupted, with emotional, psychological and behavioural repercussions;
- a focus on respite as intervention maintains (and possibly exacerbates) rather than alleviates familial difficulties requiring placements.

Of particular significance is the early focus on the child as central in family difficulties, a burden of responsibility likely to considerably increase the trauma of placement.

The UK research literature reports that the majority of children who enter the care system remain only briefly (DoH 2000; DoH 1998; DoH 1995a; DoH 1991a). Anecdotal information in Western Australia confirms this pattern, as does the recent New South Wales report (CSC 2000). What is not known, however, because of the 'snap-shot' nature of much data collection, is the proportion of short-term placements which are for 'repeaters'. Nor do we know how many times such children are placed – without any recognition of being in long-term care, albeit on a serial rather than a continuing basis. Once again, the New South Wales report confirms this pattern, stating:

> NSW does not collect data on number of placements per child, or of different care situations for each child who enters and exits care in one year. It is not possible to ascertain if some children are experiencing multiple placements because of poor case planning, placement breakdown or if they are in and out of care as a result of a planned use of respite or shared care, etc. It is therefore not possible to establish if

> NSW has been able to address the problem of 'drift' in care. This is a fundamental requirement given the known detrimental effects of instability in care on a child's social, emotional and academic developments (CSC 2000:19).

It should perhaps be noted that children may revert to the status of *repeater* when, as part of planned reunification, they are required once again to move between home and placement. Again, there has been insufficient research into the implications for children of prolonged periods of uncertainty whilst attempts are made (and it appears that several attempts are common) to return them to live with their birth families.

The movers

Movers are those children who experience multiple placements within the care system. The transient nature of the care experience is well documented (DHSS 1985; O'Sullivan & Wood 1994; Owen 1996; CSC 2000) and a large proportion of children and young people who are in out-of-home care for more than a very brief period will fall into this category. Indeed, the literature indicates that some of the older children and young people in the care system experience not only multiple placements, but also experience periods whilst still formally in care where they are effectively unplaced. Instead they live on the streets or in self-chosen placements that may or may not receive formal endorsement as safe environments. Once again, this situation was reported in the Perth study.

The stayers

These children, many of whom will have experienced a period of instability and transience, are placed *long-term* in a care setting. However, even in a long-term placement there is still an element of transience and unpredictability for many children, and in particular for those placed in residential institutions rather than with foster families. In part this transience is the result of current legislative and policy frameworks and the trend common in English speaking countries to use out-of-home care as the intervention of last resort. It reflects also the current fluidity of the care environment and the inevitable changes in the personnel caring for the children. Because of this *culture of transience* the definition of a stable placement can be made only post hoc. Although they may in fact remain in one placement for a prolonged period, many children and young people still experience a sense on transience and uncertainty, with inevitable negative impact on their sense of identity and emotional health. As one participant noted in relation to this group:

> Even here, children still don't have a sense of future certainty. Children rarely move to long-term carers where it works out. The system focuses on returning home at all costs — it's very difficult to get [agencies] to respond to anything else.

SUGGESTIONS FOR IMPROVEMENT

Participants in the study argued for an earlier and clearer recognition of each child's 'journey through care' (Fahlberg 1995) such as is facilitated by the typology of care presented in this paper. They emphasised the need for priority to be given to:

- the clarification of roles and responsibilities of all involved in the provision of health care for children in out-of-home care;
- a child-focused and individualised approach to the health and wellbeing of children in care;
- an increase in health care resources for this population;
- for younger children, the provision of readily available health screening and remedial developmental services;
- for older children and young people, improved mental health facilities;
- for all children, consistent, trained and 'user friendly' health professionals, possibly in a central location where children's health information could be maintained.

Above all, participants noted the need for a consistent, caring adult able to 'hold' the child's history, from the first time of placement, and to ensure the coherence of their life-story, emphasising the intricate linkages between a clear, positive sense of self, past and future, physical and mental health and behaviour. One participant stated this need as follows:

> The only language for small children *is* their behaviour. We all need narrative coherence. Being able to tell one's story and to know one's life story, one's life journey, is the mark of mental health — to be able to talk about and to have a narrative that makes sense from the beginning, right through. Discontinuity of experience makes it very difficult. How can you make sense if nobody else has made sense? Someone needs to keep the child's journey in mind.

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