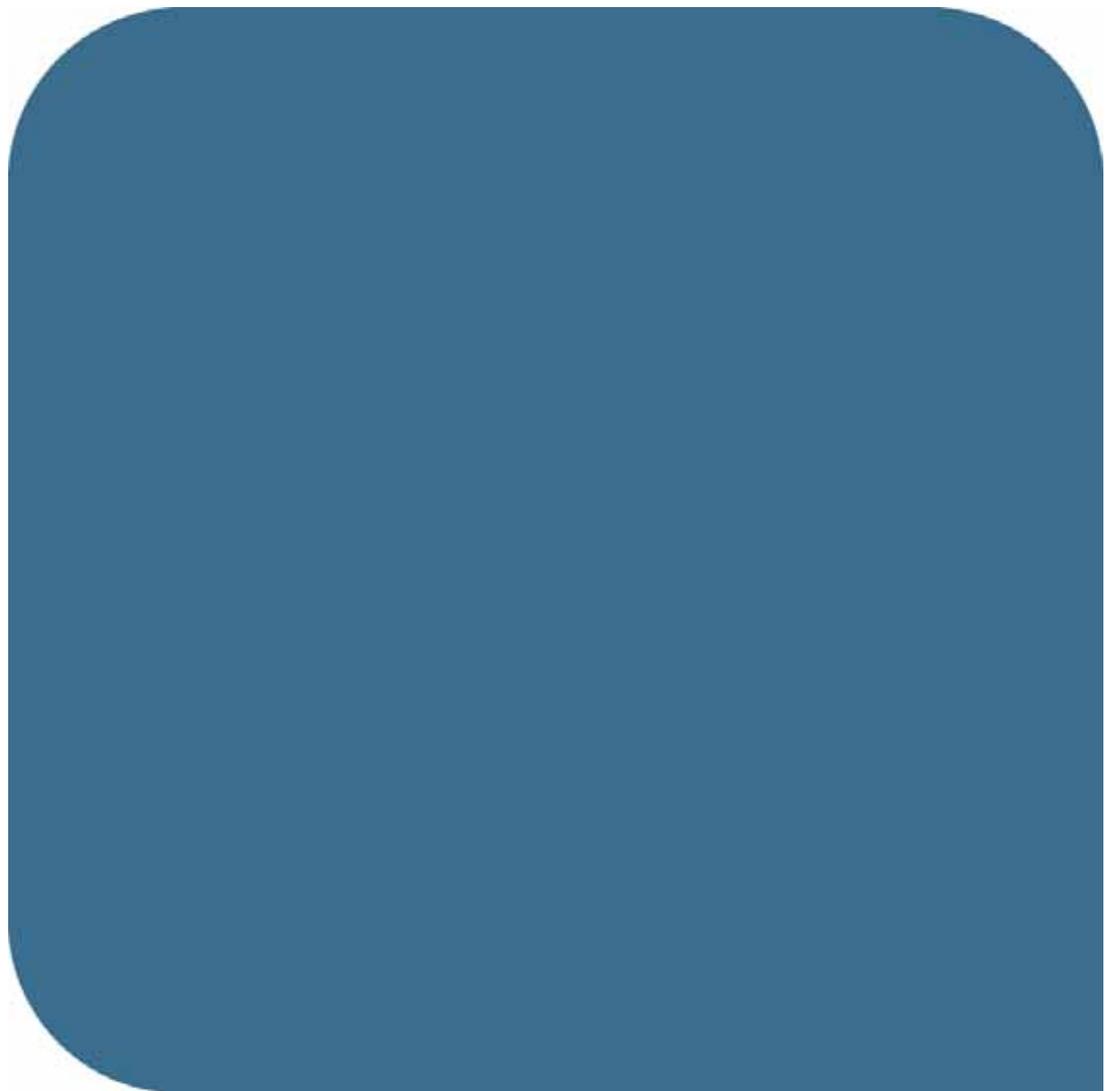


Adult placement in England

A synthesis of the literature



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December 2004

Introduction

As the first stage of the person centred approaches and adult placement project, a synthesis of findings from selected literature about adult placement was commissioned by SCIE in August 2004. The project also included a practice survey and an analytical report comparing the results of the synthesis and the survey.

The search methodology

In early 2004, a search of the literature about adult placement was carried out by Chris Reid and Janet Homewood of SCIE's Work Programme Support Team. The following databases were searched:

- ASSIA (Applied Social Sciences Index and Abstracts): large US and UK database covering a wide range of social science articles
- CareData: large UK-based social care database maintained at SCIE
- Health Management Information Consortium (Department of Health Data, King's Fund Database, HELMIS Health Systems Database): UK-based aggregated collection of health service management records
- IBSS (International Bibliography of the Social Sciences): international database covering the fields of economics, political science, sociology and anthropology
- SIGLE (System for Information on Grey Literature in Europe): European database on grey literature
- Social Services Abstracts: US-based resource
- Social Work Abstracts: US-based resource.

The date limit used for searching was 1998-2004 (i.e. 5 complete years). Database thesauri were used where available (ASSIA, CareData, Social Services Abstracts). The general approach was to include terms (plus variants) such as learning disability or learning difficulty, adults, and foster care or placement. If more than 50 search results were found, the search was refined. If less than 50 search results were found, the results were scanned for relevant records.

Aims

This report aims to bring together and distil the key literature on adult placement, looking at:

- policy and regulatory context
- facts and figures
and
- the perceptions and experiences of life in an adult placement.

Because the literature about adult placement is so scant and diffuse, no attempt is made to analyse the data or draw conclusions from it. The implications of the literature will however be drawn together with the findings of the practice survey in a final analytical report.

Context

Adult placement-type services (long- and short-term accommodation and / or support provided to a disabled or vulnerable person in an ordinary family home) have been in existence for a very long time. Perhaps the oldest formally constituted service is Geel, in Belgium, where for hundreds of years people with long-term mental illness and learning disabilities have lived and worked with families in the community, with support and back-up services from the local psychiatric hospital¹. In England, the Liverpool Personal Service Society has been providing family placements for about 30 years².

Adult placements and small homes

Despite its long history, adult placement (adult fostering / family placement) has not until recently been clearly defined and has had an uncertain legal status. The *Registered Homes (Amendment) Act 1991*³ was enacted to give protection to people living in small homes (fewer than four residents), but did not separately define adult placements. Although guidance⁴ issued in 1992 introduced the idea of 'lighter touch' regulation for adult placements, the distinction between an 'adult placement' and a 'small home' remained unclear⁵.

Concern about lack of regulation of adult placements continued to build during the 1990s. Two national surveys of adult placement services and the effect of the 1991 Act, funded by the Joseph Rowntree Foundation in 1995⁶, were critical of the lack of clear guidance about the 'lighter touch' approach: adult placement officers regarded the worst effects of legislation to be extra bureaucracy, over-strict application of regulations locally and the associated loss of adult placement carers; registration officers regarded the legislation as confusing and weak especially regarding the protection of users. These findings were published together with the results of surveys of service users and carers⁵, which found inconsistency of application of regulations to adult placement carers, and confusion and anxiety among carers. The authors recommended exemption of adult placement carers from registration, and replacement by a more effective system of regulation which would include an 'approval system' for schemes. They suggested that registration alone would not effectively safeguard service users and recommended 'well run, well resourced services with clear, documented standards, contracts and regular monitoring and review processes' to protect users and support carers (p.87).

In 1996 the National Association of Adult Placement Services (NAAPS), which represents adult placement schemes, adult placement carers and service users, launched a code of practice setting out the principles and elements of good practice as

the basis for self-regulation⁷. The publication in 2000 of best practice standards for adult placement schemes followed an audit of existing practice and a year-long consultation exercise⁸. In anticipation of a new regulatory regime, the National Association of Adult Placement Services also campaigned for regulation of adult placement schemes, pointing to intense concerns within the sector that regulation of individual adult placement carers would be overly onerous and impractical, and would result in much adult placement activity remaining unregulated and a loss of adult placement carers providing accommodation and personal care^{9 10 11}.

Regulation of adult placement carers

Despite these concerns and widespread support for the regulation of schemes, the *Care Standards Act 2000*¹² placed responsibility with the adult placement carer as the registered person to meet the requirements of regulation. In recognition of the small-scale, domestic nature of adult placements, separate regulations and national minimum standards (NMS) for adult placements providing accommodation and personal care were issued in 2000 alongside those for care homes for younger adults¹³. The Department of Health also produced policy and practice guidance on adult placement schemes¹⁴, under the provisions of Section 7 of the *Local Authority Social Services Act 1970*, setting out how adult placement schemes should support adult placement carers to meet their legal requirements, including selecting and training adult placement carers, matching and placing service users with adult placement carers, and monitoring the placement.

From the outset, however, there was 'strong adverse reaction'¹⁵ from the adult placement sector (including the National Association of Adult Placement Services, the Association of Directors of Social Services, MENCAP and the Association for Real Change) about the registration of adult placement carers as care homes; many individual adult placement carers found the registration and inspection regime burdensome and intrusive, and they resisted pressure to become small businesses^{16,11,17}. A National Association of Adult Placement Services survey of 40 adult placement schemes, carried out in 2002, reported a total loss of up to 26 per cent of adult placement carers (nearer 35 per cent for short-break carers)¹⁸. The National Association of Adult Placement Services' figures were supported by an internal survey commissioned by the National Care Standards Commission (NCSC) between January 2002 and October 2003, which also found that 26 per cent of carers decided to limit their support to people without personal care needs or to leave the adult placement sector altogether¹⁹. Anomalies also appeared regarding benefits for adult placement users and carers²⁰.

In 2003, a Department of Health consultation document proposed specific amendments to the regulations and national minimum standards²¹, including easements to the requirement to register, intended to make them more relevant to adult placement carers. It also indicated an intention to consult further on the regulation of schemes. An analysis of the responses to this consultation found general support for the proposed changes,

and strong support for the principle of regulating schemes rather than individual placements²². The National Association of Adult Placement Services welcomed the changes²³, as did the Association of Directors of Social Services (ADSS), which also proposed a concerted development programme and best practice guidance²⁴. The subsequent Care Homes (Adult Placements) (Amendment) Regulations 2003 made changes to the original regulations²⁵.

Despite this approach, the Department continued to receive strong representations from within and outside the sector, highlighting the significant loss of adult placement carers, the danger of an increasingly unregulated sector, and inconsistent standards of performance among adult placement schemes leaving some service users unprotected; and pressing for registration of schemes rather than carers^{16,26 27}.

Regulation of adult placement schemes

In light of these continuing concerns, in December 2003 a further consultation document²⁸ was issued inviting comment on the Department's proposals for moving the focus of regulation from individual adult placement carers to adult placement schemes and on draft regulations and national minimum standards. The responses to the consultation²⁹ – from schemes, individuals and organisations – were overwhelmingly positive, with almost all of the 68 respondents supporting the proposals to regulate adult placement schemes rather than individual adult placement carers. Many respondents (including the National Association of Adult Placement Services), however, felt that the draft national minimum standards remained inappropriate for some types of placements. The Association of Directors of Social Services (ADSS) and the Commission for Social Care Inspection (CSCI) – established to replace the National Care Standards Commission in 2004 – suggested a smaller number of core standards.

A survey of adult placement schemes undertaken for the National Association of Adult Placement Services and Topss England in 2004³⁰ confirmed respondents' fears of a loss of adult placement carers. In the 12 months preceding the survey a total of 441 carers had cancelled their National Care Standards Commission registration and about one-third of these had left schemes altogether. Most schemes were limiting their support to non-personal care to avoid registration, leaving only one third of adult placement carers registered with the National Care Standards Commission at the date of the survey. The burden of regulatory requirements was cited by schemes as the most common reason for problems in recruiting and retaining adult placement carers. A flurry of journal articles reacted to the National Association of Adult Placement Services / Topss survey and supported the shift to regulation of schemes³¹³²³³³⁴.

New regulations and national minimum standards for adult placement schemes came into force in August 2004³⁵. These provided a legal definition for adult placement: 'Adult placement offers short- or long-term accommodation and / or care or support provided to a maximum, at any one time, of three adults, placed through and supported by an adult placement scheme, by an adult placement carer approved by the scheme'.

Services may include accommodation with care or support (including support funded through the Supporting People programme) in the adult placement carer's home, day services or respite care inside or outside the adult placement carer's home, and 'kinship' or 'outreach' support in the community.

The new regulatory approach aimed to lift the burden of regulation from individual adult placement carers, allowing them to focus on their role in providing family-based placements; to place legal accountability on schemes to meet regulatory requirements; to ensure that *all* adult placement activity is regulated; to enable provision of a diverse and flexible range of adult placement services with and without personal care needs; and to promote the growth of adult placements¹⁶. The national minimum standards set out seven key standards covering choice of placement; individual needs and choices; lifestyle; personal and healthcare support; concerns, complaints and protection; environment; and the role and conduct of adult placement carers³⁵. Implementation of the regulations and standards, including inspection of schemes, is undertaken by the Commission for Social Care Inspection and is monitored by the Department of Health. A tool for evidencing the standards, developed by the National Care Standards Commission for the inspection of adult placement carers, is now under review by the Commission for Social Care Inspection³⁶.

Wales, Scotland and Northern Ireland

The Welsh Assembly published regulations for adult placement schemes in 2003 and national minimum standards for adult placement schemes in March 2004 (schemes were registered from August 1st 2004)³⁷. These superseded regulations and national minimum standards, placing responsibility on the adult placement carer as a care home, which had come into force in May 2002.

In Scotland, national care standards for adult placement services were issued in 2003 under the *Regulation of Care (Scotland) Act 2001*³⁸. Adult placement schemes are to be regulated in Scotland from April 2005. The Northern Ireland Assembly are also intending to regulate adult placement schemes; draft national minimum standards were issued for consultation in October 2004³⁹.

Facts and figures

Until recently, few firm facts have been known about adult placement schemes or their workforce⁴⁰. In 1993 the National Association of Adult Placement Services produced a Services Directory listing 250 adult placement schemes in Great Britain; an updated Directory (1999-2000)⁴¹ recorded about 5,000 adult placement carers and about 7,500 service users, but the impact on schemes of regulatory and other changes since then meant that this data was soon out of date.

In a study of social and personal characteristics of adult placement carers in Manchester providing services to people with learning disabilities, Gage⁴⁰ found that a 'typical' adult placement carer was a middle-aged, married woman with grown-up children. He suggested that 'an undervalued section of society is being cared for by another under-valued sector' (p.644), and called for more research.

As recently as 2002, the Government's Community Care Statistics on supported residents (adults) in England did not include discreet data on adult placements⁴². The first annual report of the Topss England Workforce Intelligence Unit, 2003, also did not separately identify adult placements in its workforce figures or discussion⁴³.

The first comprehensive survey of adult placement schemes, workforce and carers in England was undertaken by the National Association of Adult Placement Services and Topss England in 2004³⁰, to provide baseline data about the 'forgotten members of the social care workforce' and to 'quantify the investment required to modernise the adult placement workforce and ensure quality services for all service users'. Information was gathered about care provision, qualification levels, training and support issues, and recruitment and retention problems. The following data about adult placement schemes, carers, service users and workforce qualifications is from this survey report.

Adult placement schemes

There are approximately 130 adult placement schemes (the survey database) in England, employing about 600 people. Scheme size varies from fewer than 10 to more than 400 service users; and from fewer than five to over 200 carers. Eighty-six per cent of schemes are run by local authorities (the remainder are independent).

Eighty-three per cent of schemes offer registered long-term care, and about half provide registered and unregistered short-term / respite care and placements under the Supporting People programme (but the report noted that government funding cuts and uncertainty about the future may affect this area of schemes' activities).

Registered long-term care is the most common form of service provision for people with learning disabilities (34.9 per cent) and for people with mental health needs (24.7 per cent), while older people and those with physical disabilities are most likely to receive registered short-term / respite care or day services in the service user's home.

Adult placement carers

There are around 5,000 adult placement carers, mostly older and of white ethnic origin. Most adult placement carers are self-employed and are paid. Fifty-eight per cent of schemes reported difficulties recruiting carers over the previous year; 41 per cent reported problems retaining carers. 'The age profile of carers is skewed towards older

age groups...[and] is likely to have implications for the nature of the relationship between user and carer and affect perceptions of dependency' (p.23).

Adult placement service users

More than 6,500 service users are supported by adult placement schemes. Of these, 71 per cent are people with learning difficulties; 17 per cent older people, 8 per cent people with mental health problems, and 4 per cent people with physical disabilities. Schemes tend to have mixed client groups.

Training and qualifications

Qualification levels of staff compare favourably with the rest of the social care sector. The national minimum standards specify qualifications for workers and staff. About 80 per cent of workers already have an appropriate care qualification. The majority of the 130 adult placement scheme managers are currently unqualified. No qualification is laid down by the national minimum standards for adult placement carers, but they must meet Topss England induction standards and demonstrate the skills and knowledge to do the work required of them³⁵. Only 12 per cent of carers have met the Topss induction standards, and schemes report difficulties accessing training for carers. The Department of Health funded a National Association of Adult Placement Services / Association for Real Change project ('Learning the ropes') which developed tools that can be used by schemes to provide evidence of skills and knowledge⁴⁴.

The adult placement experience

Perceptions of adult placement

Within and outside the UK, there is a perception that adult placement is uniquely enabling, user-focused, valuable, and cost effective. There is little research-based evidence, however, to support these claims.

Hirst¹¹ refers to '... plenty of anecdotal evidence among social workers of the benefits of a one-to-one caring relationship' offered in adult placement. A number of journal articles over the last decade have described the benefits to service users of this model of social care, describing adult placement as, for example, the 'epitome of community care'⁴⁵ and 'one of the unheralded success stories of the shift to community care'²⁰.

The regulatory impact assessment accompanying the 2004 regulations and national minimum standards claims 'Adult placements have proved to be a valuable service option for a wide range of people including people with learning disabilities, older people

and people with mental health needs'¹⁶. The Topss / National Association of Adult Placement Services 2004 workforce survey calls adult placement a 'valued model of social care', 'increasingly recognised as a valuable and flexible service option'³⁰.

Three Social Services Inspectorate (SSI) inspections noted (and praised) adult placement services, but gave few details. An SSI inspection of services for disabled people in Bolton in 2002⁴⁶ found '...there were positive examples of developments [in line with an inclusive model of disability] in the adult placement scheme' (p.2), and recommended expansion of the service. The only specific reference however was to a befriending scheme valued by service users (p.33).

In 2003, SSI carried out an inspection of learning disability services in nine councils in England, looking at progress made toward delivery of principles set out in 'Valuing people': rights, choice, social inclusion, independence⁴⁷. The report noted a lack of adult placement schemes in some councils which was 'a serious omission as such schemes were well liked by carers and offered a cost-effective solution to the challenge of re-providing services'. The sole (and very brief) example of good practice (Leicestershire) noted that family carers particularly valued this short-term break scheme and its flexibility, and the 'positive relationships that developed between the family and substitute carers' (p.23).

A Social Services Inspectorate inspection of short-term breaks for disabled and older people (focusing on how arrangements affected carers) found that the Croydon Partners in Care Scheme was a 'well thought through and praiseworthy way of providing short-term breaks within 'real homes' that were small registered homes' (not referred to as adult placement) (p.9), but recommended developing breaks in service users' own homes⁴⁸.

A 1999 study of older foster care residents in the USA⁴⁹ found some 'common assumptions' underlying foster care placement: that family settings are inherently superior to institutions and that foster care represents the 'least restrictive care environment'. It found that, 'compared with their knowledge about nursing homes, policymakers' and practitioners' knowledge about adult foster care programs, their clientele, and, in particular, the decision to enter such [a foster care] setting is scant'. Other researchers also called for more – and more thorough – research^{5,40,50,51}.

Many journal articles also extolled the virtues of adult placement^{2,11,17,50,52}. Supporters of adult placement include the Director of East Sussex Social Services⁵³ who referred to the 'scandal' of only 6,500 placements in England, and a service user and member of the National Forum of People with Learning Disabilities⁵⁴ who wrote about losing her much-loved placement because her carer could not cope with registration.

Service users' views

Robinson and Simons⁵ noted that 'Fundamentally, the impact of all the structural changes on adult placement services, whether those are positive or negative, are only important if adult placement services are worth preserving, and to a large extent that judgement can only be made by service users. Yet there has been relatively little information about the views of users in relation to adult placement services' (p.31).

Describing an adult placement service for people with learning disabilities in Ireland, Kelleher⁵⁰ notes 'Very little research has been carried out on the views of children or adults who actually use family based respite'.

Several research projects, described below, have studied service users' experiences of and satisfaction with adult placements. As there are so few such projects, exploring different user groups in different situations, it is difficult to compare and draw conclusions from the findings. Given that adult placement is valued for its focus on individual need, it is perhaps surprising that the literature search did not produce any studies of person centred planning / working in adult placement services. A scan of the CareData database of recent literature about person centred planning turned up nothing specifically related to adult placement.

People with learning disabilities

Robinson and Simons' study of people with learning disabilities in adult placements found that 'Most people wanted to stay in their long-term placements⁵. However, there appeared to have been little attempt to help the minority who would have liked to live elsewhere' (p.55). People were mainly positive about their short-term placements, but 'their responses to our questions suggested a feeling of powerlessness and lack of ability to influence events around them.' Carers consistently identified one of the factors defining adult placement as a 'strong emphasis on family life' but researchers found a few services that 'did not appear to constitute "family life"' (p.76.) The authors summarise the areas of main concern to service users with learning disabilities – house rules, privacy, keys, transport, telephone, money, holidays – and conclude that adult placement 'particularly provided what many users wanted' (p.78).

A research project in Northern Ireland evaluated adult placement 'shared care' services for older carers and their relatives with learning disabilities, with particular reference to service users' perspectives⁵⁵. The study concluded that the main benefit that schemes offer is a break for carers. But individuals with learning disabilities 'get the opportunity to participate in a range of activities both in the home but also in community settings' (p.49), including more opportunities to socialise with non-disabled people. The author raises the ethical dilemma of carers refusing an opportunity for their relative to have a short break, perhaps ignoring the wishes of the disabled person. 'In part these dilemmas can be solved through person centred planning that actively involves the person, ... and starting this process when the [carer is] younger' (p.53).

The views of people with learning disabilities in adult placements were gathered as part of a Tizard Centre study⁵⁶ of user focus groups and Best Value in services. Overall the group 'reported positive experiences of adult placements and wished them to continue' (p.481). Service users talked about the family nature of their placements, and said that their carers were 'kind' to them. They reported mixed feelings about their reviews (supportive, frightening); and were confused about the differences between their placement officer, care manager, social worker and keyworker.

Minority ethnic people

Although the majority of carers and users are of white ethnic origin, comparisons with census data 'suggest a higher representation of people from ethnic minorities among adult placement carers than the general population'³⁰. The National Association of Adult Placement Services / Topss survey found only a minority (5 per cent) of non-white service users, suggesting that 'some minority ethnic groups are experiencing difficulties in accessing adult placement carers' (p.23). People with learning disabilities (the majority of adult placement users) who are also from a minority ethnic group are 'often doubly disadvantaged', despite the priority given to ethnic minorities and to learning disability in the *Race Relations Act* and in 'Valuing people'⁵⁷.

People with mental health needs

In 2003 Schofield⁵¹ carried out a systematic review of evaluation studies of the effectiveness of 'adult foster care' as an alternative to psychiatric hospital. The review highlighted the low profile of adult fostering among mental health professionals. While the studies raised a number of methodological issues about evaluating services, the limited evidence suggests adult placement may be a viable alternative to acute in-patient care as well as to long-term hospitalisation for people with chronic mental health problems, 'particularly in terms of improved social functioning' (p.26), justifying further research.

An earlier paper by Grove and Membrey⁵⁸ on mental health day services and social inclusion called for a 'paradigm shift' in assumptions on which day services are based. 'First they want someone to talk to who will understand them and accept them for what they are. Second, they want something to do.' The authors suggest 'an employment focus based on individual placement and support is likely to be effective in meeting the needs and aspirations of services, and can play a vital role in helping them recover a normal life' (p.22).

Writing about the need for better regulation and adult placement carer competencies, the vice-chair of the British Association of Social Workers' mental health group believed that adult placement could be of great therapeutic value but noted the possible damage to clients with mental health problems and their families if things go wrong¹¹.

Older people

In the USA study, Reinhardy and Kane⁴⁹ looked at older foster care residents' decision-making role in the move to their placement. They found that nearly half saw themselves as having had complete or almost complete control over the decision to move, and that a perception of a high level of control predicted greater satisfaction with services, as well as more activity in the home. Family members provided a major influence on the move, but one that 'appears to dampen rather than support a sense of control'. The study data 'cannot tell us where in the sequence of decision making clients are more likely to see the decision as out of their control' or whether once lost a sense of control can be regained.

People with physical disabilities

A Social Services Inspectorate inspection of short-term breaks for physically disabled people found that younger adults were not always happy with their breaks because there was 'not enough activity or independence' (p.10)⁴⁸. Nothing else about people with physical disabilities emerged from the literature search.

Young people / transition

The literature search revealed nothing about young people at the transition stage. The aims of 'Every child matters'⁵⁹ are 'ensuring every child and young person has the opportunity to fulfil their potential, and that nobody falls through the net' (p.3). But there is no mention of disabled young people and transition (and nothing about adult placement as a continuation of fostering).

Summary and conclusions

The synthesis of the literature on adult placement, undertaken for SCIE in August 2004, confirms that remarkably little qualitative or quantitative research exists about this small but highly regarded sector of social care. Much of the material relates to concerns from the sector about the regulation of services, and the development of the current regulatory system. Other sources – mainly journal articles – describe individual placements or schemes and / or offer anecdotal evidence of the value of adult placement. Only a few studies explore the quality of adult placement services or the perspective and experiences of the people who use them. Overall, the literature asks more questions than it answers – for example:

- Do service users choose adult placement or is it 'the' option offered to them?
- Once a person is in the placement, with a placement agreement, to what extent is he / she in control of decision making?
- How effective are adult placement processes in enabling service users to make changes in their lives or to move on?
- Are adult placement processes (National Association of Adult Placement Services, national minimum standards) person centred, or more or less person centred than other services?
- Is person centred planning as developed for people with learning disabilities the right approach for adult placements?
- Is the current mix of types of adult placements (e.g. short- or long-term, outreach) driven by demand or do service users fit existing, available services?
- Does adult placement suit some client / age groups better than others?
- How does a long-term, one-to-one adult placement relationship affect the people in the placement?
- Are service users involved and included in the community?
- Will the regulation of schemes stabilise the adult placement sector?
- Do the national minimum standards for adult placement schemes provide a sufficient tool for judging good practice in adult placement?
- Does the pool of adult placement carers sufficiently match the needs of prospective service users regarding age, gender and ethnic origin?
- What prevents people from black and minority ethnic groups using adult placements?
- Are the skills and knowledge, and training and support, of adult placement carers appropriate to the job they are asked to do?

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