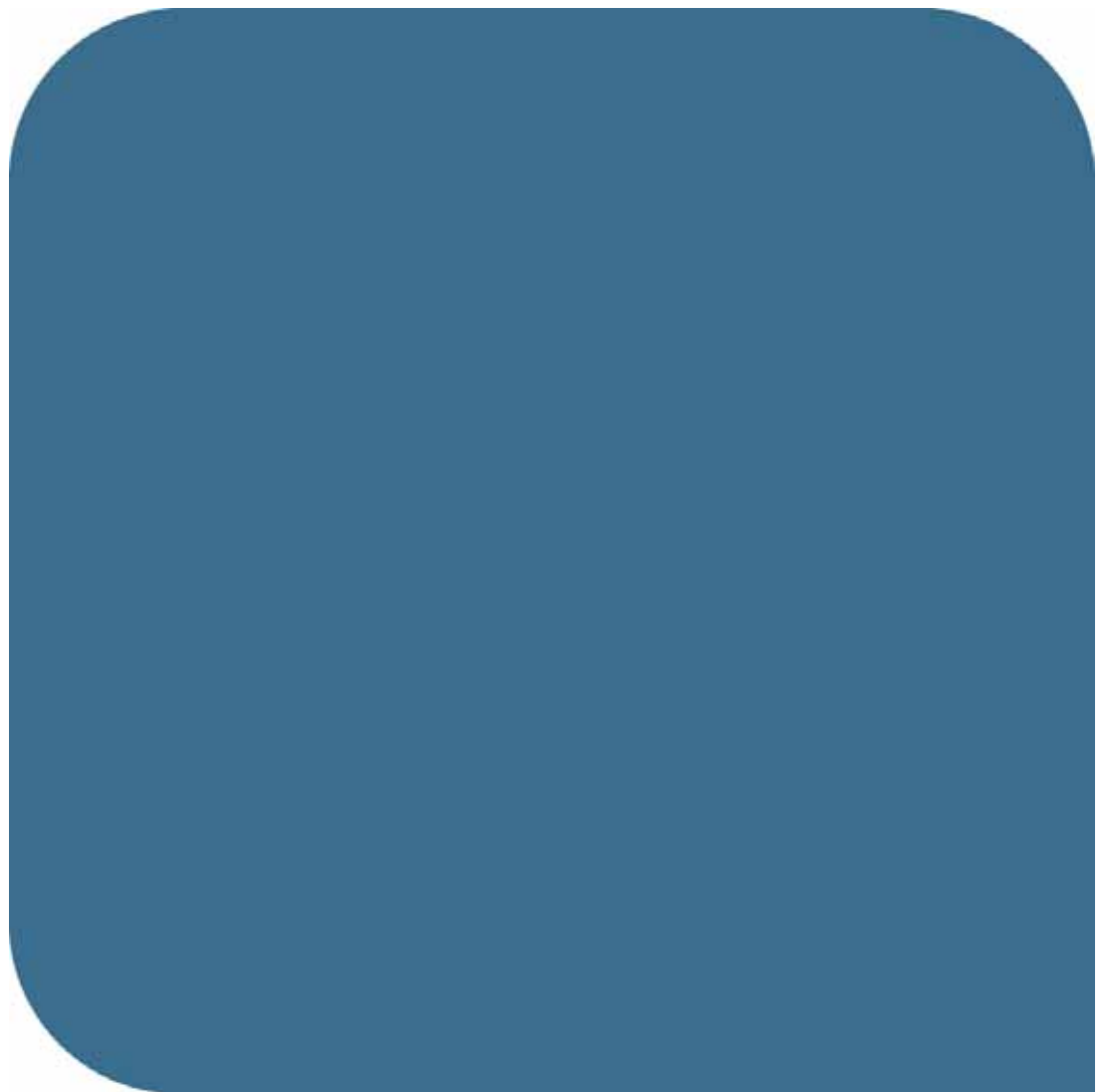


Person centred approaches and adult placement

Report of the practice survey



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Introduction

Aims

In July 2004 SCIE commissioned a practice survey as part of a study of person centred approaches and adult placements.

One of the key strands of the government's 'Valuing people' white paper for people with learning disabilities is the importance of 'person centred approaches' that lead to services based on what the disabled person wants, giving people more choice and control over their lives. In principle, adult placement offers a unique setting in which an ordinary family can provide person centred support to a vulnerable person. While current models of adult placement appear positive, however, it has not been clear whether and how person centred approaches are contributing to successful outcomes for service users. The practice survey therefore explored the ways and extent to which adult placement helps the person in the placement live as they choose; and how adult placement services benefit from person centred planning approaches developed in traditional settings.

This report of the practice survey aims to identify emerging and developing practice where person centred approaches have successfully been applied to adult placements. Two additional reports were produced for the project: a synthesis of findings from a literature review, and an analytical study examining key issues from the synthesis and survey.

Methodology

The fieldwork was carried out by Barrie Fiedler, Project Consultant, and Sian Lockwood, Chief Executive of the National Association of Adult Placement Services (NAAPS).

Two-day visits were made to four adult placement (AP) schemes selected for size and type, user groups served, and geographic location (see scheme profiles, below). The schemes were all well-established and recognised by the National Association of Adult Placement Services (and through inspections by the National Care Standards Commission / Commission for Social Care Inspection) to have a track record of successful placements. Informal, semi-structured interviews were carried out with the scheme manager and staff team members, and with adult placement carers and service users in four placements for each scheme.

The half-day scheme interviews were conducted jointly by the project consultants. The agenda for the meetings (advised by letter and in telephone discussions) was to explore:

- scheme processes and practice, from referral to review, and how they deliver what is important to the person in the placement
- what helps (and what hinders) person centred working
and
- whether the scheme's way of working has changed as a result of 'Valuing people' and the development of person centred planning theory.

'Person centred' was defined in the 'Implementing valuing people: Toward person centred approaches' guidance as 'activities which are based upon what is important to a person from their own perspective and which contribute to their full inclusion in society'. We clarified the difference between person centred *approaches* and person centred *planning*. Particular attention was paid to decision-making, and the involvement of the person, at each stage of the process.

Following the session with scheme staff, each consultant carried out (approximately) two-hour interviews with adult placement carer(s) and service user(s) in two placements. Carers and users were interviewed together and / or separately as appropriate (write-ups of interviews with four service users are included as Appendix 2). The criteria for schemes' selection of placements were that the person should be living in a long-term placement, and be able to communicate with the interviewer (with support if needed). We asked schemes to try to include a wide range of ages, types and levels of disability, and duration of placement. Discussions with adult placement carers and the person in the placement covered the same broad agenda as for scheme teams, focusing on choice and decision-making and on things that support or prevent person centred working.

Schemes also arranged for us to talk to others involved with the person in the placement: we interviewed, in person, three social workers / care managers, and one advocate via telephone.

Scheme profiles

At the time this practice survey was undertaken, participating schemes were at a transitional period between the old and new regulatory systems for adult placement. The following profiles describe the situation at the time of our visits, when a scheme might have 'registered' and 'unregistered' placements prior to registration as an adult placement scheme with the Commission for Social Care Inspection.

Adults Supporting Adults (ASA), Lincolnshire

ASA provides community services for people over the age of 18 years who have a learning or sensory disability or mental health needs, including people with dementia, and who require support to live in the community. The scheme employs 19 permanent staff and 65 temporary / relief 'ASA providers' (adult placement carers). The scheme has been in operation since 1989, and is in the process of becoming independent of the local authority.

There are 69 self-employed Adults Supporting Adults providers, of whom 14 are registered, providing either long-term placements (for 10 people with mental health problems and 45 with learning disabilities) or short-term placements (for up to 60 people with mental health needs or learning disabilities per annum). Community Service Daytime Provision (one-to-one or small groups, in community facilities or in the provider's home) supports 93 people with learning disabilities and 15 with mental health needs. Twenty older people with dementia are supported through At Home Day Services by six providers in the providers' home. Another 10 providers employed by At Home Day Services support 12 people with mental health problems and six with learning disabilities.

Brent Adult Placement Service (APS)

Launched in 1981, Brent adult placement service provides long- and short-term placements for 44 people aged 20 to 79, supported by 26 carers, most of whom have worked for the scheme for many years. Thirty-one of these placements are unregistered, funded through Supporting People. Twenty-three service users have a learning disability, 11 have a mental health problem and 14 are older people. There is a staff team of six.

Most service users have lived for many years in their placements (originally the scheme placed people for life), with few opportunities for change. Following a period of some difficulties for the scheme, Brent adult placement service is beginning to recruit new carers and seek new referrals, and to help people to move on. Several staff members, adult placement carers and service users are participating in Brent Social Services' person centred-planning pilot project.

St Anne's Community Carers Scheme (CCS), Leeds

St Anne's CCS was set up in 1992 and provides long-term placements in the Leeds metropolitan area for people with learning disabilities. CCS is part of St Anne's Community Services, a registered charity which was founded in 1971 and which includes a variety of housing- and accommodation-based support, day services and community-based support for homeless people and those who have mental health or substance-misuse problems or learning disabilities.

The scheme currently has 33 self-employed carers supporting 37 service users aged between 21 and 94. The staff team comprises a scheme manager and two community carers (adult placement workers).

Supported Accommodation Team (SAT), East Sussex

The SAT in East Sussex provides both adult placement (up to three people) and supported accommodation (over three people). There are 231 people accommodated overall in the scheme, with further available vacancies, of whom 123 have learning disabilities (the remainder mainly have mental health problems). Within adult placement there are 70 (registered and unregistered) adult placement carers; 52 carers support 86 people with learning disabilities. Thirty-nine of these were previously registered carers (66 placements)—i.e. long-standing, small care homes re-assessed and approved by the SAT when the *Care Standards Act* came into force in 2002.

The Supported Accommodation Team operates from three area teams, with three senior practitioners and 14 supported accommodation officers currently covering adult placement and other supported accommodation provision. The Supported Accommodation Team is in the process of reorganising in light of the new regulatory requirements for adult placement in order to clearly show the two aspects of their service, although the same standards of assessment and review are applied to both adult placement and supported accommodation.

Service user and adult placement carer profiles

Most service users we visited had a learning disability, and some had a mental health problem or dual diagnosis; their ages ranged from 23 to 94 (most were in their 50s and 60s). They had been living in their placement from six months to 20 years. While all the placements were long term, some had originated as emergency placements or short breaks, and several people also had experience of other short-term ('respite') placements.

Service users and adult placement carers in the four schemes were predominantly White British / Irish; of those we interviewed, two service users and one carer family were Black / Asian. In two scheme localities—Leeds and Brent—a high proportion of the population is Black or Asian, and scheme staff hope to expand the schemes' work in these communities.

Adult placement processes

During interviews with scheme staff we explored how the scheme's processes, from referral to review, identified and delivered what is important to the person. All the schemes participating in this project were working to achieve good practice systems and processes for adult placement as established by the National Association of Adult Placement Services' good practice standards and model policies and procedures, and the national minimum standards (NMS) for adult placement schemes. We did not assess schemes' written policies and other documents.

Assessment and referral

Most people in adult placements—all those participating in this project—access funding through local authority care management / care coordination. In theory each person referred will have had a social services needs assessment and a care plan which identifies how the person's needs and preferences will be met through adult placement. In practice this is rare in older placements. In the four schemes visited only those recently referred had a care management assessment or care plan, and the quality of information about people referred to schemes is often poor. In one locality, social services produces an assessment and care plan in parallel with the scheme's assessment, identifying the selected adult placement carer as meeting the person's assessed needs.

All schemes visited carry out their own, detailed individual assessment of the referred person.

St Anne's Leeds adult placement workers try to find out about and talk to as many people as possible who know the referred person in different settings: key workers, parents, psychiatrists etc. The worker meets with the person on their own in a variety of environments to get to know them better. This process is particularly important if the referred person has limited communication.

Schemes are working on documents to help improve referral information. The Supported Accommodation Team, E. Sussex has developed a two-part accommodation assessment which includes a client statement (user's views) and a statement of professionals' views. The team considers wider service options for the referred person, not just those provided by the scheme. Adults Supporting Adults, Lincs have revised their application form for care managers; their referral-progress record sheet helps keep the referral on track.

Social workers (and the general public) in three of the four scheme localities were reported often to be unfamiliar with adult placement. Partly because of its recent expansion, Supported Accommodation Team, E. Sussex has a higher profile. St Anne's, Leeds gives talks about the scheme to local care groups, People First, and service user forums, and receives many direct referrals, who are referred on to social services.

(Sometimes this is the first contact the individual will have had with social services, and the first contact social services will have had with the adult placement scheme.)

Sally's social worker first became involved with Sally when her terminally ill mother was referred for nursing care. He had not previously known about the adult placement scheme, which was suggested by the learning disability team. The social worker liked this idea because Sally had always lived in a family setting.

Scheme staff noted that referrals are affected by social workers' Best Value decision-making. Until the recent capping of funds, people were being referred ('pushed', one scheme said) for supported living funded through Supporting People. Adults Supporting Adults, Lincs receive many more referrals now: adult placement is again 'best value'. In East Sussex, social services often refer people for assessment by the scheme to demonstrate they have considered the cheaper option even if they do not intend to place the person in adult placement. Brent reported that under Fair Access to Care eligibility criteria only those with high care needs were receiving assessments, and social services were ruling out adult placement as providing insufficient support.

Key findings

- Many social workers / care managers / care coordinators are unfamiliar with adult placement.
- Few people referred for placement have a care management assessment or care plan, and the quality of information about the person referred is often poor.
- Referrals are influenced by funding availability (e.g. Supporting People), and therefore not always needs-led.

Matching and introductions

The matching and introduction of an individual with an assessed and approved adult placement carer is one of the key person centred tools of adult placement. Because schemes may know little about the person referred, and the referred person know little about adult placement (see Assessment and referral, above), the matching and introductory processes are especially important in ensuring the placement is right for the person (and carer).

Meeting all a person's preferences and needs, and achieving a 'perfect' match, is seldom achievable. All four schemes visited had a limited pool of carers. Offering the referred person a choice of placements is not always possible although all the schemes visited aimed to do so. The person is likely to be offered the 'choice' of the match the scheme thinks will be the best fit, focusing on the issues that are most important for user and carer. If the person and / or carer do not think the placement will work, a second or third option may be offered. If no suitable match is initially found, the worker may go back to the person and the carer to check how important a particular factor is to

them and whether there is room for negotiation or compromise. A placement will not be made if no appropriate match is available.

Nasa had never had a pet, and was afraid of dogs. A key issue for Nasa was a placement where there was no dog. The adult placement worker found an adult placement carer who seemed a good match for Nasa, except for the family dog. The worker discussed this with Nasa, who agreed to meet the family. After several visits Nasa found that she quite liked the dog, and agreed to try out the placement.

Schemes stressed the importance of taking time—commonly six months to a year—to develop and test the match between user and carer. Flexibility is required however: the East Sussex team said that some learning-disabled / autistic people were distressed by the long introductory process, or could not cope with an overnight stay; a few people had decided after an overnight visit that they did not want to leave. If the referred person has low comprehension, the adult placement worker may first show the person's social worker the placement options.

Adults Supporting Adults, Lincs occasionally advertises for a carer for a particular individual if that person has very specific requirements. A scheme may also facilitate and formalise a match developed between a prospective service user and carer outside the scheme processes.

John, aged 94 with learning disabilities, wanted to leave the hostel where he had lived for 20 years (previously he had lived in a large, long-stay hospital since age 17). The other residents were too noisy, and John wasn't allowed to come and go when he wanted. Lynda worked at the hostel where John lived, and John would often meet Lynda's husband Hal when Hal picked up Lynda from work, and show him his photographs. Occasionally John attended events at Lynda and Hal's home. Lynda had heard about the scheme, and when she became increasingly unhappy working at the hostel, she and Hal agreed to talk to John about living with them. After a number of visits organised through the scheme, John said he didn't want to go back to the hostel any more. At Lynda and Hal's it was quiet, he had his own room, and he could go out and about whenever he wanted.

One challenge for a scheme is to arrange a suitable match for someone who has had little experience of life outside a protected (family or care-home) environment, and who has limited interests, expectations and / or ambitions.

Carla lived with her father until he died, and had been 'spoiled' and overprotected. When she came to live with Penny, she began to learn to look after herself (personal hygiene, diet) and to develop a sense of her own personality. After a while people said they did not recognise her: Carla was far more confident, and she had lost weight, chosen a new hairdo and clothes, and learned to help with cleaning, cooking and laundry. Carla now has an active social life and Penny is working with her to safely cross roads / take buses so she can get about more independently.

Several people interviewed had taken up the interests of the adult placement carer.

Dan does not take part in any activities outside the family. He enjoys doing the things his carer George does—in particular bird watching, recently becoming a member of the RSPB in his own right, and has become genuinely enthusiastic about it. He has also joined the Order of the Buffalo with George and is working his way up through the ranks. Dan also attends a club for people with learning disabilities where George helps out.

Sometimes the referred person may not have the life experience or capacity to fully understand the concept of adult placement—or even the concept of family. One adult placement worker noted the difficulty of making choice a reality when the person might say they like any carer visited; the worker felt she actually decided for the person.

Phil, now in his 60s, whose parents both had learning disabilities, spent his childhood in a Barnardo home but was moved to a mental hospital when he became disruptive. By the time he was 18 Phil was sleeping rough and had severe mental health problems and a criminal record, as well as learning disabilities. Phil had no personal experience of family life and did not really understand what adult placement meant. Phil was placed with Sue and Rob on an emergency basis nine years ago—mainly because they were prepared to have him. The placement proved successful, and was made permanent, not as a result of person centred pre-placement processes but because the scheme and carers worked slowly and carefully with Phil, helping him especially with communication, relationships, sexuality, and focusing on ‘what he *can* do’. (See Interview 1, Appendix 2.)

Another potential difficulty for schemes is balancing the different views of parents, social workers or others about an individual’s wishes, needs or best interests. One parent, for example, had persuaded their adult daughter to refuse a placement because they were concerned about her safety and about losing touch. The adult placement worker maintained contact with the family over a period of months, helping them to understand what was important to their daughter, giving them a chance to reconsider as they learned more about adult placement and began to trust the adult placement worker.

A common pathway into long-term adult placement was through a short-term / emergency placement, either with the scheme’s own short breaks service (Lincs, Brent, E. Sussex) or local authority provision (Leeds). Occasionally a successful placement seemed to result from good luck rather than planning.

Sameera was unhappy with her adult placement carer. When the carer needed medical treatment, the adult placement worker found her a short-break placement with the only Asian carer available. After a very short time Sameera decided she wanted to stay there. The worker set up a number of meetings with Sameera and her translator at the day centre to make sure Sameera fully understood and wanted to make this decision. The worker then supported Sameera to visit the previous carer to say goodbye, and

supported the carer to deal with Sameera's decision to leave. (See Interview 3, Appendix 2.)

Careful monitoring of the placement by adult placement workers during the early stages ensured that everyone could be confident—whatever the method of getting there—that the match was the right one in practice (or the placement ended if proved otherwise).

Key findings

- Placements are usually the best match available, not an ideal match.
- A successful placement may develop from a short-term / emergency placement as well as from following 'textbook' person centred adult placement processes.
- The person referred may have little life experience for making a decision about where to live.

In the placement

All service users we visited felt strongly that the placement was their home, and that the adult placement carer was their family. Individual choices and activities were discussed and agreed between the adult placement carer and the person on a daily basis. All carers in placements we visited were supporting people on a day-to-day basis to make choices and be more independent. For the person in the placement, these are the things that matter. Written plans seemed of marginal importance to most service users and carers, and some were not aware that a placement plan existed.

Placement agreements

Adult placement model policies and regulatory requirements call for a placement agreement, including a service user plan, to be agreed between the service user, adult placement carer and scheme, and funding body. Some thoughtful plans had been developed with people recently placed by the schemes we visited; people in long-standing, unregistered placements however may not yet have a placement agreement.

After a lengthy assessment and introductory period, Daniel, who is recovering from drug abuse and subsequent mental health breakdown, was placed with Sheila and Michael. A placement agreement was drawn up before the placement started in order to 'trigger' the funding (along with a licence agreement and housing benefit application). Daniel, his mum, mental health team key worker, adult placement worker and Sheila all contributed to the placement agreement meeting, and everyone signed and had a copy of the agreement. The agreement set out what Daniel wanted from the placement and what everyone was going to do: Michael will work with Daniel to develop a daytime routine and handle his medication better. Sheila and Michael had produced a short introduction

to the house and family which includes practical information (e.g. telephone and internet access); the scheme's 'house rules' (around confidentiality and respect) and some specific rules for the household (e.g. smoking, guests, privacy). (See Interview 2, Appendix 2.)

Service user plans could not be set in stone. Particularly in the first months of a placement, changes are often made to the plan as established preferences are revised in light of new experiences.

Roy's service user plan specifies weekly swimming, as his mother had said he loved swimming and insisted on this. In the first eight weeks of the placement many activities were offered and Roy did not choose to swim. At the eight-week review Roy did not list swimming as one of the activities he wanted to continue.

User and carer support

Schemes acknowledged the challenge of changing the practice of some older, long-term carers. Some carers (including former foster carers) found the new regulatory requirements and documentation an imposition (and a few were openly hostile: one carer said the placement plan 'won't change anything—just filling out a form'). In longer-standing placements, Supported Accommodation Team, E. Sussex spoke of 'going slow' in putting in place new placement plans, 'ratifying'—rather than risk upsetting—existing arrangements. The scheme also spoke of 'winning over' old-style carers to a more person centred way of working; one carer called it an 'evolutionary approach'.

In the best practice adult placement model, the scheme supports the adult placement carer, and the whole placement, while the social worker / care coordinator retains responsibility for the service user. In practice, very few service users have an active social worker / care coordinator; cases are generally closed following placement and initial review. When asked where they would go if they had a problem or needed help with something, service users named their adult placement carer without hesitation. Several also named a close relative; only one named a social worker.

As social work involvement has decreased, adult placement workers in several schemes are increasingly taking on the social-work role with service users, supporting both the user and carer in the placement. This can create difficulties and conflict for schemes and carers: several carers interviewed clearly resented their adult placement worker's shift of focus to the service user (see Person centred issues). The schemes we saw took different approaches to this problem. Of the four participating schemes, Adults Supporting Adults, Lincs was the only one where social workers remained engaged once the placement was settled.

Kevin's social worker is very supportive, visiting three times yearly, and attends his twice-yearly care-plan review (along with Kevin and his cousin who is his 'advocate'). Short breaks and transport are arranged (and rearranged) quite speedily when required.

Kevin chooses to go to his day centre rather than stay at home for the adult placement worker meeting, so he rarely sees the adult placement worker. Kevin's adult placement carers find the Adults Supporting Adults scheme very supportive – 'second to none'. (See Interview 4, Appendix 2.)

Supported Accommodation Team, E. Sussex were also clear that support for service users is the responsibility of social workers, but cases are usually closed or sent to Duty after the initial review period; adult placement workers informally pick up on issues regarding the service user at their monthly carer visits.

In St Anne's Leeds, adult placement workers see the carer and user on their own and together to obtain a sense of the quality of the relationship (and feel these regular visits are more important than formal reviews). The worker writes up each visit, following up any concern, for example visiting the person outside the placement (e.g. day service), and checking with others who know the person well. The worker may contact social workers but this is of limited value as they see service users so rarely. Brent Adult Placement Service also has a policy of supporting both user and carer.

Short-term breaks

Providing suitable short-term breaks was sometimes an issue. Schemes support adult placement carers to have (but do not necessarily provide or fund) regular breaks. Short breaks for service users may be provided in local authority placements (St Anne's Leeds), the scheme's own placements (Adults Supporting Adults, Lincs), in local authority care homes (Brent Adult Placement Service), or a combination of these (Supported Accommodation Team, E. Sussex); or by approving family or friends to provide short breaks. In some families, the person placed always holidays with the adult placement carer (some carers and users did not think they needed time apart).

Several Adults Supporting Adults, Lincs carers interviewed, who offered short-break placements in addition to one or two long-term placements, said that their long-term service user was consulted about, and was able to meet in advance, the prospective short-break referral. Several service users confirmed that they were content with occasional short-term additions to the family home.

Some adult placement carers' relatives had been approved by Brent Adult Placement Service and Supported Accommodation Team, E. Sussex as adult placement carers to provide short breaks, so the person in the placement could remain at home while the main carer was on holiday or having a short break. This seemed the most satisfactory arrangement. One service user interviewed wanted a non-family 'respite' carer to stay at the house, but the carer was not happy with this.

Peer support

Service users in Leeds and Brent were participating in user groups, for peer support and to put forward their views on services; the groups were at early stages and attendance was poor. A group of carers in Brent—ex-nurses who live in the same community and know one another—have formed a carers' network, independently of the scheme. A support group of adult placement carers from St Anne's Leeds is not well attended because, its organiser believes, carers are content with the scheme.

Key findings

- Some long-standing (unregistered) placements do not have a placement agreement and service user plan.
- Service users and carers believe day-to-day support, choices, and activities are more important than written plans or goals.
- Social workers rarely remain engaged once the placement is settled.

Annual reviews

Regular review of the placement and service user plan is required by regulation, and an annual review of the care management care plan is required by Fair Access to Care Guidance.

Users and carers were frequently unclear about the purpose of and difference between these reviews (sometimes they were merged), and between reviews and scheme monitoring visits. For users, carers and sometimes adult placement workers, annual reviews were seen as a requirement, not a positive experience.

Several service users said they preferred to go to their day service rather than attend the review meeting. One worker felt that requirements 'imposed' on the review meeting could create tension 'as some things have to be talked about and some people must be there, even if that is not what the person wants'. Several carers saw reviews as an 'intrusion'. Others resented the review's emphasis on the service user rather than the carer.

St Anne's, Leeds tried to make the review the person's meeting, establishing in advance what the person wanted to talk about and who would be there. An example was given of a user turning up to a review not knowing what was going on because the social worker was 'not doing her job'. Pre-review meetings between the adult placement worker and the person can ensure that there are no surprises for the person at the meeting, and that the person is aware of any decision that needs to be made. (Many service users associate meetings with being told off or having to move.) The workers try to find an appropriate place to hold the meeting to elicit the best feedback from the person: for example, one person won't talk if the adult placement worker is carrying a notebook; another won't talk in her day centre. A series of shorter sessions may be easier for the person, talking about one particular issue at a time.

Lee dreads and detests review meetings. The adult placement worker has tried to make the review as tolerable as possible by keeping the meeting informal and limiting the number of people who attend. The adult placement worker learns Lee's views on issues that may arise through informal meetings, chatting in the worker's car or over a cup of coffee. The carer encourages Lee to put his thoughts on tape and this is played at the review meeting.

The role of social workers was again called into question. Service users rarely had a named social worker who knew them well who could attend the (placement or care management) review. Sometimes a duty / review officer attended, but frequently there was no social services representation. One carer said that as a result 'problems are not sorted out'. One social worker said he uses the scheme's annual review as the basis for the required care management review. He thinks in future more reviews will be done by telephone (as is currently the case for reviewing clients in care homes).

'Moving on' is often identified as a long-term goal in placement agreements (though not the aim of most of the service users we interviewed)—see Moving on, below. Several people placed with Brent Adult Placement Service were involved in a social services person centred planning pilot and were working toward independent living (see Person centred planning, below). Adults Supporting Adults, Lincs has a formal, planned move-on model of adult placement.

Razia, who is 37 and has learning disabilities, came to live with Yana six years ago. Razia had low self-esteem, temper tantrums, a continence problem, and was quite uncooperative for the first two years. In 2000, with the help of a person centred planning pilot project, Razia and Yana, with Razia's day centre key worker and advocate, drew up a 'map' of Razia's life and identified independent living as her goal. Razia began an independence-skills training course at college, where she also writes poetry and is involved with a self-advocacy project. She is learning to self-medicate and to budget, manage her post office account and remember her pin number. A supported living place has been identified for Razia.

When asked how they judge when a placement is successful, scheme staff all stressed 'gut feeling', based largely on observation; they 'can tell' if something is going wrong, even if they can't put their finger on it. Other terms used by workers to describe how they could tell if things were going well included:

- what users say
- the way [user and carer] talk about and react to each other
- feels right
- atmosphere
- I know
- body language

- common sense
- they're happy.

Workers acknowledge that these subjective feelings need to be backed up by evidence, which may come from within or outside the placement. They spoke of 'getting lots of different angles', and 'looking beneath the surface, reflecting on what you saw and heard'. An adult placement worker in Leeds said worker supervision is important in checking out their own reactions to their feelings about the placement. Positive indicators suggested by scheme staff include:

- carers achieving 'knowledge and skills statements' in National Association of Adult Placement Services' 'Learning the ropes'
- person starts to talk about moving on
- person able to talk more freely about their feelings
- good balance of respect and compromise between user and carer
- person's confidence and self-esteem grow
- person is known in local shops
- others note 'amazing change' in person.

Indicators of problems in the placement included increased contact with the placement, bad behaviour of the service user, complaints by the user or carer, the carer not being willing to work with the scheme, or the user looking after the carer (though this might occasionally be appropriate, e.g. a person with mental health problems caring for another user while the carer was in hospital might be 'in everyone's best interest').

Key findings

- Service users and adult placement carers are unclear about the difference between placement reviews, care plan reviews, and other monitoring meetings; and do not find them particularly helpful.
- Social workers are not active participants in reviews.
- Adult placement workers rely on subjective criteria—'gut' feelings—to judge the success of a placement.

Person centred issues

Person centred planning

Person centred planning (PCP), as defined in 'Valuing people' guidance, 'is a process for continual listening and learning, focusing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends.' Person centred planning provides the basis for and promotes person centred approaches ('ways of commissioning, providing and organising services rooted in listening to what people want'). There is no single 'best' way of doing person centred planning; a number of different 'brands' or styles of person centred plan are marketed (e.g. Essential Lifestyle Planning; Personal Futures Planning; MAPS and PATHS).

All four participating schemes were committed to person centred values. Schemes were clear that adult placement is founded on the relationship between user and carer, and that carers' attitudes and values are the key to person centred practice. Schemes said that adult placement carers are given clear expectations of their role at recruitment, and sign up to a way of working that focuses on the individual. 'Valuing people', with its promotion of person centred planning, has brought these issues more to the front of schemes' minds. Formal person centred planning, however, did not have a high profile in any of the four schemes, and the term 'PCP' is not used in scheme documents.

St Anne's, Leeds believes the organisation has always had a person centred focus; Adults Supporting Adults, Lincs also believes the scheme's person centred approach was in place before 'Valuing people' and the promotion of person centred approaches / planning; and Supported Accommodation Team, E. Sussex spoke of its person centred team ethos. Recognising the need to change 'a long culture of "doing things" for the service user' and to meet new national minimum standards and Supporting People requirements, the Brent Adult Placement Service manager has produced draft proposals to restructure the team and to work in a more person centred way. Scheme staff spoke variously of treating the person as an adult, as he or she wishes to be treated; of their role in helping adult placement carers to understand and practise person centred working; and of practices 'designed around individuals with individual needs'.

Scheme staff questioned the commitment to and practice of person centred working in the local authorities with / for whom they worked. Brent and East Sussex councils had set up person centred-planning pilot projects but these were affecting only a small number of people.

Most adult placement carers were at best vague about person centred approaches / planning, and only a few could describe what 'person centred' meant. Several however were enthusiastic. One Brent Adult Placement Service carer and participant in the local authority's person centred-planning pilot said person centred planning is 'a great guide—you have to listen, write it down, talk to [the person]'. Another carer said 'it

makes you think, not make assumptions'. A recently approved carer said that although he may not use the words, he is aware of being 'subconsciously' person centred, and of working differently from other, long-standing carers who have an 'old school', production-line approach to daily routines for service users.

Not everyone was enthusiastic about person centred planning however. One man (who shares a placement with Razia whose person centred plan is described above) refuses to have a plan—'he doesn't like the interference'! One carer said it was not easy doing person centred planning—the person placed with her needs support with decision-making, and can't deal with questions like 'what do you want to do'. Some scheme workers were sceptical about the benefits of formal person centred planning: one said a service user might be forced to attend his review when he did not want to be there; another thought asking about 'dreams' for the future just upsets people.

Several scheme staff spoke of real life dilemmas in attempting to realise a person's 'dream':

Raymond is besotted with Yasmin who also has learning difficulties. His dream is 'for Yasmin to live here'. Adult placement carer Gordon does not have a problem with this if the relationship is consensual. He talks to Raymond about kissing being ok if she says yes, but thinks Raymond does not fully understand the concept of a sexual relationship. In addition, Yasmin needs personal care, but Gordon (a single man aged 39) will not provide personal care for a woman, so Raymond would have to move in order to achieve this dream—something he is adamant he does not want to do.

Service user Teresa and her adult placement carer Katherine, aged 69 and 72, are not much interested in 'dreams'; they just jog along companionably, exploring hobbies they both enjoy.

Key findings

- Formal person centred planning does not have a high profile among scheme staff or adult placement carers (or local authorities).
- Informal person centred working can be effective.
- People's 'dreams' are more likely to be about who they live with than about where they live; and more about daily life than about the future.

Moving on

All schemes visited are increasingly working towards a model of adult placement as a 'stepping stone' toward living independently (see also Annual reviews, above). In St Anne's, Leeds, moving on / going independent is kept on the agenda for review meetings, especially with younger people. The scheme feels their role is to recognise and take the initiative when it is time for someone to move on. In Adults Supporting

Adults, Lincs moving on is discussed at monthly meetings with the service user and adult placement carer, and with families, day centre staff, advocates, practitioners etc., as well as during the 'hopes and wishes' session of adult placement workers' monthly supervision. Adults Supporting Adults staff gave several examples of carers helping the person during the transition to more independent living, and keeping in touch afterwards on a planned and paid basis through ASA's Daytime Provision service.

Adam was found with severe amnesia but was identified through a missing-persons trace as having local links. Unable to cope in social situations, Adam would become distressed and go into foetal position. He was placed with Tony and Anita who over 18 months familiarised him with the area, creatively supporting him through his trauma. Adam began to go out on his bicycle so he could speed away when he saw someone he knew. Tony and Anita supported a renewal of his relationship with his four children, and through his training to become a nurse. Now a qualified nurse, Adam lives independently but has continuing contact with his former adult placement carers.

Leaving the placement can be challenging for service users who have lived many years in a placement, and who agreed the placement on the understanding that it was 'for life'. Independent living was rarely the goal of the people we visited, even where identified as a long-term goal in their plan. Several seemed alarmed at the suggestion that they might not always be able to live with their adult placement family; several specifically stated that they wanted to stay there forever.

Misha and Nicky share a placement with Razia (see box above) who is actively planning a move to supported living. Misha (who has mental health problems) also has a 'map' and person centred plan which identifies moving on as her goal, but she is not motivated or ambitious to do so; moving will be 'in her own time'. Nicky refuses to have a plan at all.

Stephen is very clear that he wants to live with the Hardys forever. He says he doesn't want to live by himself or to share a house with someone else who has a disability. He likes his life and wants it to carry on.

For some this view might change over time with increased confidence and skills, but for others 'for ever' seemed the ideal future. (Several carers said a person (see Clive, below) may say living independently is his goal because that is what he thinks is expected of him and what he should want. E. Sussex scheme staff thought they had 'no right to move them if they are happy', but also that the scheme had a responsibility to move someone inappropriately placed in an expensive setting. They pointed out that a person may not want to move but might be happy when they do so (see Gary, below).

Clive, who is 29 and has a dual diagnosis, has lived with the Wilsons since he was six (the Wilsons became adult placement carers so that they could continue to care for Clive; he sees the Wilsons as his parents). Clive says that he would like to have a flat of his own one day but this deadline keeps slipping. Five years ago his social worker offered him a flat of his own— Clive has avoided this social worker ever since! The

Wilson's work with him on daily living skills, but doubt he will ever achieve 'his' goal of independence.

Gary identified so strongly with 'home' he did not want to leave his 'respite' care home; but after a series of visits with Joe, and repeated explanations that he could not stay at the short-break care home, he came to see the new placement as 'home' and is now absolutely happy there.

Supporting a person to move on can be difficult for a carer: because of the closeness of the relationship, the carer may feel they are failing or betraying the service user. The scheme needs to help the carer acknowledge that the placement is no longer right for the person. Additionally, most carers are financially dependent on placement fees: long waits between placements, together with lack of severance pay, can be a disincentive to supporting the person to move on, encouraging the carer to hang on to a placement that does not work. Planned move-on may also be delayed or thwarted by a lack of appropriate accommodation for supported housing (a social services responsibility); the wide and expanding range of options offered by Supported Accommodation Team, East Sussex is unusual.

Moving on might be necessary, even though this is not the person's choice or a positive change. When a carer chooses or is forced to retire, the service user must 'choose' from alternatives provided by social services (though in practice, the scheme often seeks another adult placement and tries to achieve a smooth transition).

Key findings

- Schemes are changing from a 'for life' to a 'move-on' model of adult placement, but in practice adult placement workers and adult placement carers proceed carefully and respect the person's wishes.
- Many service users say they never want to leave their placement (even if moving on / living independently is a specified long-term goal).

Adult placement carer training

All the participating schemes saw their role as supporting carers to understand, accept and practise person centred ways of working. Managers and staff spoke of the importance of both pre- and post-approval training for adult placement carers, and of an 'evolutionary' approach to changing the practice of traditional carers. The National Association of Adult Placement Services' 'Learning the ropes' was thought helpful.

While many carers we interviewed valued the training offered by the scheme, not all were convinced that training was important.

Despite a background in care, and relatives who have been adult placement carers, Saleem believes that pre- and post-approval training is definitely valuable in helping him support the particular needs of the people placed with him (especially on challenging behaviour, medication, and safety) but also to give him confidence in his attitudes and working methods.

Christina appears disinterested in the scheme's training and carer support (and confused the two)—being an adult placement carer is 'common sense', 'love and affection'. She goes when she can and could only recall doing first-aid and medication training—"they talk about this and that".

The Smiths take advantage of the range of training courses offered, though they have never heard of person centred planning or 'Valuing people', and have not been offered training specifically targeted at the needs of the person placed with them.

Olive only does essential training (e.g. first aid) as carers are expected to contribute to the cost of training.

Sharon has done essential training but believes what matters is 'the type of person you are' and 'learning as you go along'. She is a nurse and fully conversant with 'Valuing people' and person centred planning principles (learned about via her own networks).

Shirley has been a carer for years and has lots of 'life experience' and is not impressed with 'young things telling me how to do my job!'

Changing working practice was particularly difficult for older, long-standing, traditional carers, who were resistant to change ('we tried it and it didn't work') or who found new requirements daunting. When E. Sussex Supported Accommodation Team expanded to include former small care homes, scheme workers re-assessed these carers and made judgements about whether with training and support they could raise their standard of caring, which existed through ignorance not deliberate bad practice.

Key finding

- Some long-standing adult placement carers believe they know best how to support the person placed with them, and do not value or attend scheme training events.

Adult placement carers' views on adult placement caring

Most of the adult placement carers we interviewed spoke of helping the person placed with them to change, grow, develop, become more independent—"You can see their

progress over all these years—it's just wonderful!' But all spoke with feeling about the importance of their 'caring' role. While a few were aware of and used the language of person centred working (see Person centred planning, above), it was clear that adult placement carers are most motivated by 'giving' and 'caring'. They see adult placement caring as 'a vocation, not a job'. They were also clear about what they gain from being an adult placement carer.

Sarah wants 'to give something back' and 'share my life'—'it's what you get out of it'.

Gina loves looking after someone—it's 'a reason to get up in the morning', 'company, love and affection', as well as 'a little money'.

Rehana believes 'you can focus on the individual, not like in a care home; and there's less red tape, it's easier to make things happen.'

Dorothy says 'It keeps me going, gives me a 'reason for living', as well as 'some extra money.'

Mildred: 'I can get paid, be at home, take the girls out. I feel good about it, and the girls are happy.'

Bejan, a single man, was not happy with his previous work and social life: 'I needed more—a family.'

Clara: 'See the results—how they've progressed, I'm so proud of them.'

While all the carers we interviewed were enthusiastic about their job, several were frustrated by changes in their roles, and felt they were not valued and were 'doing it wrong' (see Adult placement carer training, above). One carer said that other professionals are not interested in their views, and don't involve them—'you're just the adult placement carer.' Several were concerned that adult placement was becoming more user- than carer-centred: meetings with adult placement workers were now 'all about service users' rights.'

The Bergers are successful, long-term carers who appear to work in a very person centred way, and think highly of their adult placement scheme. However, they feel that the scheme now focuses more on and cares more about the person placed than about them. At the annual carer review, the scheme worker now has to talk to service users about their views of carers—this should be the carers' time. They attribute these changes to 'the government', 'the system' (regulatory requirements), not the scheme. They resent twice-yearly inspections by National Care Standards Commission / Commission for Social Care Inspection, despite consistently 'high marks'.

Although several carers noted that they did not earn much money as adult placement carers, none suggested that this contributed to their feeling undervalued.

Key findings

- Where there is no social-work support for the person in the placement, the adult placement carer may resent the adult placement worker's attention to the service user and feel less valued by the scheme.
- Adult placement carers are motivated by what they gain from being an adult placement carer as well as by the happiness and progress of the person placed with them.

Family life

In adult placement, family dynamics seem more important in achieving a 'good' outcome than pursuing a person centred planning 'dream'. In the successful placements we saw, the people placed were doing what was important to them, from their perspective, within the boundaries of family life. Adult placement carers were also fulfilled. The give and take required did not feel like restriction or compromise but like the behaviour of responsible adults in a family setting.

The adult placement model of living as a family unit can however create tensions between the user's and the carer's needs, and requires a different interpretation of being person centred. Schemes addressed conflicts through negotiation with user and carer and through carer training.

One St Anne's, Leeds worker spoke of service users as adults with responsibilities as well as rights: 'It is patronising to say the user is always right.' Service users may expect to 'have things their own way' or 'feel they are owed everything', but need to learn to fit in, give and take, be thoughtful, compromise. By learning to live within a family, the person learns to manage in wider society outside the placement. The adult placement model requires some restriction on the total independence of, and control by, the service user. Sometimes a placement can only continue if boundaries are put on some behaviours (e.g. noise, late nights)—sometimes referred to as 'house rules'—which acknowledge the equality of everyone in the household.

Although ground rules had been set about an appropriate time to come home at night (9:30 during week, 11:30 at weekend), Karim pushed the boundaries later and later. The adult placement carer felt responsible and stayed up until he came in. After involvement by the scheme, the social worker talked to Karim explaining the carer's point of view. Eventually a compromise was reached and new ground rules agreed, which were acceptable to both.

When adult placement carer Monica became ill, service users Rachel and Sarah wanted to stay in the placement. Sarah, who has mental health problems, and is very

protective of Rachel, was able temporarily to take on some housekeeping and support tasks so that the family could stay together.

Key findings

- There can be tensions in an adult placement between the adult placement carer's and the service user's needs and rights.
- Adult placement requires the give-and-take and compromise of family life—no one in a family can just do what they want without consideration of others.

Birth families

Some people had close links with their birth families, and in some placements the birth and carer families had become close.

Claudia has good contact with her relatives, and her birth and carer families have become close. When Claudia's carer Fiona's sister died, Claudia wanted to go to the funeral but Fiona was too distraught, so Claudia's sister took her and they took part in the family service.

Not all family contact was positive: parents could cling to decision-making and financial responsibility; or not want their child to have a sexual relationship.

Frankie's parents continued to exercise control over the placement, 'directing from the wings', restricting new activities, and insisting old patterns were followed. Frankie lacked the confidence to resist her parents' influence (and did not have an advocate). Eventually the placement broke down.

An adult placement carer may take on a parental role and have trouble letting go ('I'm sort of their mum—I treat them like my own children', claimed one carer).

Minnie, an older carer, found it difficult to allow Debby more independence in the placement. Over a period of four years the scheme worked carefully with both carer and user. Initially Minnie was persuaded to 'allow' Debby some day-care support and then a short break away. Eventually Minnie was able to recognise that Debby wished to move on.

Key finding

- Family contact is important, but continuing inappropriate parental / family control over decision-making and money can deter independence.

Advocacy

Advocacy services were limited in all four participating schemes. The service users we spoke to saw their adult placement carer (and occasionally a birth family member) as the person who would carry out the advocate's role of speaking up for them and representing their interests. Only one service user interviewed belonged to an advocacy group and was actively supported by an advocate (see box).

Chrissy is a member of the Speaking Up Group at her day centre, facilitated by the local advocacy organisation. Chrissy's advocate, Sue, worked with Chrissy to decide the agenda for her annual review, making sure that the issues important to her were discussed, and that enough time was taken to deal with them. Sue also supported Chrissy to make a formal complaint about a problem at her short-break home. Chrissy says 'if someone bullies you, Sue will speak up for you'. Chrissy is helping make a film about self-advocacy to help other people with learning disabilities.

One service user had had an advocate during the transition to adult placement, but because the person did not know the advocate well, his carer thought the service was of limited value. Another service user received good advocacy support during a legal case, but the advocate was no longer involved.

Key finding

- People in adult placements rarely have independent advocates.

Social inclusion

Adult placement is defined by the opportunity it offers people to live an ordinary family life in the community. All the service users we visited were part of their adult placement carer's immediate and extended family, and shared family holidays with the adult placement carer. Carers and users thought their neighbours and local shops were friendly and helpful.

Most of the people we met spent some time in jobs, day services, or college, and a few spent time on their own out and about in the community. Several people were out all day, every day (some adult placement carers also have day jobs). Service users were generally happy with these activities, and some were enthusiastic: John who has a paid

job at the local stables; Phil who looks after trolleys at a local shop; Peta who does odd jobs for a garden maintenance project. Ben chose his placement in part because of the freedom it gave him to come and go as he pleases, and Elaine likes to go round the shops with her carer. Donald prefers to take part in bird watching and other activities enjoyed by his carer.

People did not always appear to have chosen their daytime activities; sometimes activities—often traditional day centres—seemed to have been arranged as part of the adult placement package because those were the local services available. A few carers, however, were concerned at how little the service user did at their day centre and tried to work with centre staff to change things or find other alternatives. A few people were frustrated at the college requirement to pass a written test.

Tony says he wants to be a mechanic. The college assessed him as unable to do the course. Tony's adult placement carer and adult placement worker talked to Tony about what he meant by being a mechanic and discovered that what he really wanted was to be around cars.

Lack of money limited what several service users were able to do, and problems with transport were mentioned by others. One adult placement carer said it was difficult for the person placed with her to see friends without the carer present, and was trying to enable them to go out together unaccompanied.

Key finding

- While adult placement service users participate in a variety of community activities, the quality of some day services is disappointing.

Summary of key findings

The practice survey aimed to identify emerging and developing practice where person centred approaches have successfully been applied to adult placements. Visits to 16 'good practice' placements selected by the four participating schemes showed that these adult placement carers were working in a person centred way with service users although they were not using formal 'person centred planning' systems. National Association of Adult Placement Services model adult placement standards and processes help schemes support adult placement carers to support service users, from referral to review, to achieve choice, independence and inclusion. Schemes were clear that adult placement is founded on the relationship between user and carer in a family setting, and that carers' attitudes and values are the key to person centred practice.

Discussions with scheme staff, adult placement carers and service users, however, highlighted a number of issues affecting person centred working in adult placement including:

Adult placement processes

Assessment and referral

- Many social workers / care managers / care coordinators are unfamiliar with adult placement.
- Few people referred for placement have a care management assessment or care plan, and the quality of information about the person referred is often poor.
- Referrals are influenced by funding availability (e.g. Supporting People), and therefore are not always needs-led.

Matching and introductions

- Placements are usually the best match available, not an ideal match.
- A successful placement may develop from a short-break / emergency placement as well as from following 'textbook' person centred adult placement processes.
- The person referred may have little life experience for making a decision about where to live.

In the placement

- Some long-standing (unregistered) placements do not have a placement agreement and service user plan.
- Service users and adult placement carers believe day-to-day support, choices and activities are more important than written plans and goals.
- Social workers rarely remain engaged once the placement is settled.

Annual reviews

- Service users and carers are unclear about the difference between placement reviews, care plan reviews, and other monitoring and review meetings; and do not find them particularly helpful.
- Social workers are not active participants in reviews.
- Adult placement workers rely on subjective criteria—‘gut feeling’—to judge the success of a placement (while recognising the need for evidence).

Person centred issues

Person centred planning

- Formal person centred planning does not have a high profile amongst scheme staff or adult placement carers (or local authorities).
- Informal person centred working can be effective.
- People’s ‘dreams’ are more likely to be about who they live with than about where they live; and more about daily life than about the future.

Moving on

- Schemes are changing from a ‘forever’ to a ‘move-on’ model of adult placement, but in practice adult placement workers and adult placement carers respect the person’s wishes.
- Many service users say they do not ever want to leave their placement (even if moving on / living independently is a specified long-term goal).

Adult placement carer training

- Some longer-standing adult placement carers believe they know best how to support the person in the placement, and do not value or attend scheme training events.

Adult placement carers' views on adult placement caring

- Where there is no social work support for the person in the placement, the adult placement carer may resent the adult placement worker's attention to the service user and feel less valued by the scheme.
- Adult placement carers are motivated by what they gain from being an adult placement carer (someone to love and care for, company, feeling valued) as well as by the happiness and progress of the person placed with them.

Family life

- There can be tensions in an adult placement between the adult placement carer's and the service user's needs and rights.
- Adult placement requires the give-and-take and compromise of family life—no one in a family can just do what they want without consideration of others.

Birth families

- Family contact is important but continuing inappropriate parental / family control over decision-making and money can deter independence.

Advocacy

- People living in adult placements rarely have independent advocates.

Inclusion

- While adult placement service users participate in a variety of community activities, the quality of some day services is disappointing.

Appendix 1: Adult placement scheme contacts

Adult Placement Service, Brent

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St Anne's Community Carers Scheme, Leeds

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Appendix 2: Sample interviews with service users

Interview 1

Phil, who is 49 with severe learning disabilities and mental health problems, was placed with Sue and Rob nine years ago. Sue and Rob have grown-up children who no longer live at home; they hated their empty house. Both were working when Phil first came to stay, but gave up their jobs and, a year later, another service user, Leonard, joined the family.

Phil's parents both had learning disabilities, and Phil was placed in a Barnardo's home as a young child. When he became disruptive, he was sent to a large mental hospital. As part of the hospital closure programme, Phil moved to a hostel but this proved unsuccessful, and when he turned 18 he left. His father took him back, and found him work on the railway—but took his salary, and got Phil to steal for him. Phil now has a criminal record. He also has mental health problems, but stopped taking his medication when he went to live with his father. Things went from bad to worse, and Phil was sleeping rough for a while. Just recently Phil has started to reveal some of the terrible experiences and abuse from his past—he had never trusted anyone before he came to live with Sue and Rob, and was afraid he would get into trouble.

Following a series of introductory meetings, Phil was placed with Sue and Rob. He hardly spoke, was obese, and quite traumatised. Sue and Rob do not think Phil understood what adult placement is—he had no concept of a 'family'. Matching was based on Phil and Rob's shared interest in outdoor pursuits (and on Sue and Rob's availability at the time).

A mental health nurse visited at first, but decided that Sue was already doing what the nurse was meant to do. Sue has worked hard with Phil on relationships, sexuality, communication, and things like 'who would you go to if you needed help'. She tried to teach Phil how to read, and he can now recognise a few words to associate with feelings (happy, sad, angry). Phil started college but could not pass the written test which is a condition of college funding, so Sue decided with Phil to concentrate on what he was able to do. Phil is enthusiastic about his twice-weekly job at the local stables. He likes all outdoor and physical activities, which he does with Rob. Although it took Phil two years to learn to swim, he loves it now.

Phil wants to be 'normal'. He does not make friends, and his life is with Sue and Rob (and their children and grandchildren). He is usually acquiescent ('he likes to do the things we do'); and is likely to say 'yes' to whatever is offered to please them, but they can tell by his face when he means 'no'. Phil needs frequent prompting for personal and household tasks, but does not need firm rules. But Phil can become angry and 'up-close'; Rob and Sue have strategies for helping him calm down, but have to be careful with him in company. They are certain that Phil knows he can come to them for support and love.

Phil has had to learn to deal with some difficult times for his adult placement family: Sue and Rob's grandchildren stayed for a while when their daughter had problems; Sue had a breakdown, and Rob had cancer. They thought that Phil and Leonard should stay at home throughout these difficulties as part of their family and growing up experience; and also believe that having Phil and Leonard at home helped them keep going through these crises.

Interview 2

Daniel, aged 22, was placed with Sheila and Michael in August 2004. He had been living with his mum, and working as a truck driver, but got into drugs which triggered a serious mental health breakdown. He was helped by the drug and alcohol team and went on a methadone programme. His key worker from that team, Al, is very important to Daniel. Daniel recognised that, if he was going to come off drugs and recover his mental health, he needed to make a complete break with his old friends and the local drug scene. Daniel stayed in his mum's house and didn't go out at all. He got into the habit of sleeping all day and staying up for much of the night. Realising that he needed to get away, Daniel eventually spoke to his key worker, Al, from the mental health team. Al told him about the adult placement team, and sent a referral in April 2004.

Al arranged to meet Peter, the adult placement worker, with Daniel at Daniel's home. When Peter arrived, however, he found that Daniel was not expecting him (Al was not able to be there) and had no idea who he was. Daniel says that Peter 'talked his way in'. Peter told Daniel about the sorts of services offered by the scheme, and—once Daniel had decided that he might be interested—visited again to talk to Daniel and his mum. Peter came back a few more times before Daniel and his mum were ready to take things forward.

Peter began a detailed housing assessment, which took three meetings, each for about an hour and a half. Peter helped Daniel to say what he wanted and didn't want in a new placement. He didn't want to live in a built up area, or too near his current home. He wanted a household which was busy but not too busy. He wanted to have things to do in the day because he wanted a reason to get up in the morning—but not too much or too structured as he got very tired. He wanted to be able to get to see his mum regularly and he also wanted to keep in touch with his sister. Peter recognised that it was important for Daniel to keep the same key workers, which limited the areas that they could look at. When the assessment was completed, Peter showed a draft to Daniel, who was able to make changes before signing the final report.

Peter identified two possible carers that met Daniel's specification. Sheila and Michael lived in a village, their home was lively without being frenetic, their adopted son was around the same age as Daniel, and they had dogs and cats and Daniel liked animals. Michael and Sheila's own children had grown up and left home but visited regularly with their partners and children; and there was also an older lodger. The other couple were

older, and lived in a small town. Peter felt that Sheila and Michael were a much better match than the others, but told Daniel about both couples, and Daniel decided to meet Sheila and Michael first.

Peter gave a copy of Daniel's assessment to Sheila and Michael. They recognised that it didn't give a full picture of Daniel and felt that it was important to meet him. In May 2004, Peter arranged to bring Daniel to meet Michael and Sheila and see their home. When Daniel arrived there was a houseful as Sheila and Michael's children had dropped in to see their parents. Daniel said that didn't matter as Sheila and Michael were so welcoming and made him feel at home straight away. They spent an hour or so together at that first visit and Daniel had an opportunity to see the two spare rooms and decide which room he might like if he came to stay. Daniel decided straight away that this was right. He didn't want to meet the other prospective adult placement carers.

Daniel came to stay for three weekends over the next couple of months. His mum brought him and she liked Sheila and Michael at once. Daniel, Sheila and Michael all found the wait before Daniel was allowed to move in frustrating. The funding process extended the delay although Peter worked hard to move things along (the placement agreement was drawn up in advance to trigger the funding; the licence agreement was drawn up and signed; the housing benefit application could only go in once a moving date was agreed).

The placement agreement meeting involved Al, Peter, Daniel, Sheila and Daniel's mum. The agreement set out what everyone was going to do and what Daniel wanted from the placement. Everybody chipped in, and signed and had a copy of the agreement.

Sheila and Michael had written a short introduction to the house and the family which gave practical information (e.g. telephone and internet access). There are adult placement scheme 'house rules' (around confidentiality and respect); and also specific rules for everyone in the household including smoking (initially smoking only downstairs but, because this caused Daniel some difficulty, changed to roll-ups only upstairs which go out if dropped); guests (Sheila needs to know who is in the house); privacy (knock on the door and wait to be invited in before entering anyone's private space).

Michael is spending a great deal of time helping Daniel develop a daytime routine that gives him a reason for getting up and does not exhaust him. Daniel tries to get to the gym several times a week. Michael begins the process of waking Daniel up at about 10am, and they go out together later in the morning. Some days Daniel finds it easy to get up; other days he spends most of the day in bed. Daniel has some difficulties around food; he gets his own breakfast, and Sheila keeps the fridge stocked with things that Daniel likes. She cooks a meal and Daniel can choose whether to eat the meal or get himself something else. Daniel doesn't much like food shopping—he will go with Sheila but under sufferance. Daniel is beginning to expand his repertory of meals, and is learning to cook the things he likes to eat.

Michael has been supporting Daniel to handle his medication better. Because of Daniel's disturbed sleep pattern he wouldn't always remember whether he had taken his medication and some days would miss it altogether or take two doses. Together they have set up a 'nomad' system which Daniel now manages; this is working well and Daniel's medication is reducing.

Daniel says that he is taking things slowly and not trying to do too much too quickly. He would like one day to have his own place and to have a job—but just at the moment he is taking one day at a time, and he and Michael are setting small goals that he thinks he can achieve.

Daniel, Michael and Sheila talked about what got in the way of helping Daniel do what he wanted to do: the delay in referring Daniel to the adult placement scheme (AI was overworked, and Daniel was not a priority as he was safe with his mother); delays in securing funding for the placement; Daniel's comparative poverty, which limited his access to community facilities; and limited access to the mental health key worker (Daniel only sees the new key worker every six weeks).

Interview 3

Sameera, an Asian woman in her late 60s with a learning disability, has lived with Nazneen and her family for five months. Nazneen has been a long-term adult placement carer for 18 years. She shares her house with her son Tariq, one of her daughters, and another service user, Megbai, who is 53 and has lived with the family for seven years. Tariq used to be a computer engineer but has recently decided to become an adult placement carer, and has been approved to provide respite support for his mother. Nazneen hopes ultimately to hand over the long-term caring responsibility to Tariq but will continue to provide respite support for him; she is training to be a counsellor.

Sameera had been married and has two sons. She became increasingly unwell and was admitted to hospital, where she disclosed that her husband had been abusing her and their sons. Sameera remained in hospital for some years. She stayed in contact with her ex-husband but her sons have not wanted any further contact with her. Sameera was discharged from hospital into the care of an adult placement carer with whom she lived for nine years.

Sameera became unhappy with that placement when the carer took on responsibility for the care of her grandchildren. Sameera felt that her carer was giving more attention to her grandchildren than to her, and their relationship began to deteriorate. Sameera told her adult placement worker that she was unhappy and wanted to move.

When the carer went away for two months for medical treatment, the adult placement worker looked for a short break placement, and Nazneen was the only Asian carer available. Sameera visited Nazneen at home and liked her, and also immediately got on

very well with Tariq. She went to stay with Nazneen and Tariq and decided after a very short time that she wanted to live there permanently. The adult placement worker contacted Sameera's care manager who was helpful and supportive. They had a number of meetings with Sameera at her day centre with a translator to make sure that Sameera was completely sure she wanted to leave her previous adult placement carer and move in with Nazneen and Tariq, and that she understood what was involved. Sameera, with support, gave her carer notice. The adult placement worker and care manager supported Sameera to visit the carer to say goodbye and collect her belongings. The adult placement worker spent time with the previous carer and her daughters, who had grown up with Sameera and were upset about Sameera's decision.

Sameera speaks limited English but expresses clearly the warmth of her relationship with Nazneen and Tariq. She seems particularly close to Tariq and enjoys outings that involve him. She says that Tariq is her 'son'—a relationship that has great significance for her. Tariq carries out some personal care tasks for Sameera (rubbing her knee with deep heat to ease the pain of her arthritis; cutting her toe nails). Sameera has high blood pressure and used to resist taking medication, but Tariq takes Sameera's blood pressure twice a week and his involvement has encouraged Sameera to take her medication. Nazneen and Tariq clearly value Sameera and all that she has brought to the family—they talk warmly of her sense of fun, and of her enjoyment of family activities.

Sameera goes to a new day centre once a week, which she likes because people there can speak Gujarati and there is much more to do (cards; darts; cooking; exercises). Sameera also goes to the local mosque when someone can take her; Tariq intends to take her more regularly as soon as he has a car. Tariq is hunting for a car at the moment and Sameera enjoys helping him with that. Sameera enjoys helping Nazneen cook—experimenting with recipes and eating the results! Sameera also likes Megbai very much: they both speak Gujarati and enjoy talking and watching Asian films together.

The whole family, including Sameera and Megbai, are holidaying in Spain in the New Year. Sameera is close to her sister who lives in Canada, whom she visits for a month every year; her sister is coming to see her at her new home. Sameera is learning to be more independent: she says that her old carer did everything for her, but now she gets her own breakfast and looks after her room by herself. Sameera has little ongoing contact with her care manager; all the support for the placement comes from the adult placement scheme.

Interview 4

Kevin is 67 and has learning disabilities, diabetes and is blind. He lived with his aunt from early childhood after his mother died, and was brought up with his cousin who is like a sister. When his aunt could no longer look after him, Kevin was placed briefly in a care home before coming to live with the Freemans.

Kevin came with his cousin to visit the Freemans, then spent two weekends with them over a period of several months. Although Kevin's social worker was not very helpful, the adult placement scheme 'filled the gaps' in supporting Kevin and, once in the placement, making sure his needs were met.

During his first year with the Freemans, Kevin suddenly and unexpectedly lost his sight following eye surgery. The Freemans registered as a small care home so that Kevin could stay with them when he became blind. With the help of an advocate, Kevin fought—unsuccessfully—for compensation for negligence (aged 65 and with learning disabilities he was a low priority, and waited ten months for surgery to re-attach a retina, but it was too late to save his sight). Shortly after that, Kevin became diabetic.

When they retired a year ago, the Freemans moved with Kevin to a smaller house in a new locality (but with the same adult placement scheme). Kevin was by then part of their family and they did not consider going without him.

Kevin is a strong character (Kevin says 'I'm the boss') and is quite capable (though he 'talks more than listens'), but has poor mobility. His daily routines are well-structured: every day Stuart, his day worker, takes him to the day centre; from there, they may go to the café, to the library, to buy the newspaper (Stuart reads it to him, and helps him with the crosswords). Kevin 'talks' to Stuart on his tape recorder, and they discuss what he wants, and does not want, to do. Kevin had never been swimming, and he and Stewart are trying this. Kevin has so much daytime activity he is tired at night, often happy to be in his room and 'watch' TV (previously when in care he sat around all day).

At home, Kevin has a cup of tea, and then breakfast, in bed. Because of his diabetes he needs regular food, so can't sleep in; the Freemans explained this to him, and offered him the choice of getting up to eat or breakfasting in bed, and he chose the latter. Kevin can get about independently at home, including getting to the wc on his own. He has a bell by the bed in case he needs help; and a talking clock so knows when to get up, when it's time for tea, etc. Kevin knows his neighbours, and is known in the local shops.

Kevin's blindness and diabetes cause some problems. Kevin won't say when he feels unwell, so the Freemans look for signs—e.g. sweating—that might indicate a diabetic attack. Kevin's fear and distress outside the house are the reason for his low mobility; he does not trust people to guide him, but pulls back and so uses a wheelchair when out (he tried the Blind Society rehabilitation service, but this was stopped because he made no progress, he would not learn to be guided). When he became blind, Kevin's mobility benefits were stopped. On appeal, a GP, care worker, solicitor, and lay person visited but could not effectively communicate with Kevin (he is apt to agree with whatever is asked or suggested), and did not see Kevin try to manage outside the house.

Twice yearly the family go on holiday together. Kevin loves travelling, especially on trains. He makes an album of photos and souvenirs for each holiday, which people can

look at and jog Kevin's memory—he loves to talk about his holidays! Kevin becomes easily disoriented when in unfamiliar settings, so prior to a holiday the Freemans do a 'virtual tour' of hotels online to make sure Kevin can get out of bed and to the wc in the same way as at home.

Kevin is very close to his cousin, who acts as his advocate, and is the person he would turn to first for help. Kevin enjoys visits and phone chats with her, and with the Freemans' family. The Freemans made clear they do not make plans and then tell Kevin, but discuss with him beforehand what they might do and when; they also talk to Kevin's cousin before making a firm plan, to make sure they are meeting his preferences. Kevin has a short break for two days each month. His current social worker is very supportive, visiting three times yearly and attending his care plan reviews (which Kevin attends along with his cousin); and is very helpful in arranging and rearranging respite and transport quite speedily to suit Kevin's plans. Although the Freemans find their new adult placement worker very helpful and supportive, Kevin has not met her—he chooses to go to the day centre instead.