Barriers cleared in ENDELL STREET

How a team in London's West End set about systematically overcoming the barriers preventing homeless hostel residents getting the treatment they needed. The key step was a simple one – asking the residents just what it was which stood in the way.

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IN LONDON'S WEST END, a stone's throw from Covent Garden and theatreland, is the Endell Street hostel.[1] Run by St Mungo's, this 'first-stage' facility houses 93 homeless men and women, most coming directly from living on the street. Among them are many chaotic, polysubstance using injectors. Most have previously experienced methadone treatment without engaging or completing, some have never been in treatment, and – before we set up our clinic – few were currently in treatment.

Our aim in a six-month pilot project was to see if we could engage and retain them in methadone treatment by siting a clinic in the hostel itself *The Endell Street pilot* p. 22. It was considered a success and in October 2003 became established as a satellite service of South Camden Drug Services. This article is about how we involved the clients in adapting the existing harm reduction approach to prescribing and used this to improve access and retention.

For most of the hostel's drug users, the route down Endell Street to treatment looked something like this.

JUST ASK (BUT SYSTEMATICALLY)

We knew that simply providing a conventional service was out of the question – our targets were precisely those residents who could not (or would not) engage with other prescribing services. First-stage hostel residents are difficult to engage and retain. Often this is due to conflicts between the treatment provider and the client over what sort of treatment is required and how it should be provided. The flexibility needed to engage people with unpredictable and disordered lifestyles may also seem incompatible with the safeguards necessary for clinical safety.

It was clear what sort of service would not work, less clear what would. Due to lack of contact and access, this client group is poorly understood. We didn't know whether they wanted methadone, could comply with the demands of treatment, and, if they

BARRIERS & SOLUTIONS

I CAN'T MAKE THE APPOINTMENTS

The most common barriers were a general sense of chaos (forgetting, not realising the time or the day) or competing priorities (having to beg or score). Some clients also expressed unease about the keyworking process itself, not always wanting to open up or engage, or not having the time for the full session. Anxiety about this and an inability to negotiate changes had often lead to a failure to attend at all.

To overcome this barrier we operate a drop-in clinic. Clients can pick up their scripts any time the clinic is open and can pop in to clinics even when their prescriptions aren't due. Sometimes it results in a queue as people wait for their prescriptions, but so far this has not presented any management problems.

Beyond the need to maintain clinical safety, clients are not expected to make a set, minimum commitment to keyworking. We expect to see them regularly, but there are no sanctions for not attending every time and no automatic threats to their ongoing treatment from missed appointments. Partly by reducing anxiety, this approach actually results in excellent attendance – 87% of keyworking appointments are attended.

We also minimise the time patients need to commit, and make the most of this time by drawing on the extensive network of professionals involved with the care of the Endell Street client group. Good partnerships with these workers mean we can build up a much fuller picture of the client's needs and target care more effectively. These links also mean that less contact with the clients doesn't compromise clinical safety.

Where before most would have fallen foul of clinic regulations, overall our clients now fulfil their end of the treatment agreement. Attendance is good, as is compliance with requests for urine samples, reviews, questionnaires and for participation in research projects.

I CAN'T GET THERE

One of the most important things about the clinic is that it is there in the hostel. Delivering prescribing services in-house has made it much easier to reach and retain patients, while the hostel's own substance use team provides support and motivation for clients during and outside clinic hours.

The pharmacy too is very near the hostel. We liaise very closely with the pharmacist, and they and their staff have been supportive of the service and popular with the client group. This relationship maximises attendance (95% of scheduled methadone administrations are completed) and minimises violence or other unacceptable behaviour from the clients.

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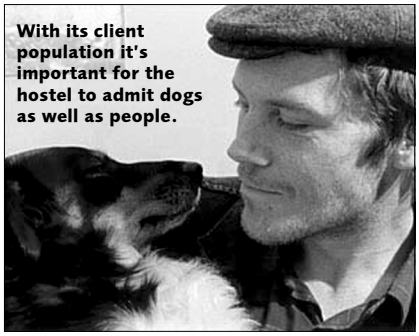
could, whether they would benefit as a result. It was important to begin with an open mind, taking clinical safety as the starting point, but then allowing the clients to shape the service. The main way we did this was through an initial client survey carried out during the pilot phase. The service continued to adapt to the client group, but this survey gave us vital clues about how to start.

Given the client group, the survey had to be short, accessible and informal. We were interested in only two issues: how did they feel about previous treatments, and what kind of service would they like? Under each heading, we asked just two questions. Dr Michael Haskew designed the questionnaire to be as simple and open as possible. In relation to past treatment, it avoided attributing blame or negative connotations to either party. We were interested only in identifying where the barriers lay.

Using this framework, hostel residents were surveyed when they first came in to treatment. Though free to refuse, none did so. The purpose was to improve our understanding of the clients, not to provide replicable statistics, so we felt free to be flexible. Some clients completed the questionnaire themselves, some gave the information spontaneously during assessment, others were briefly interviewed.

Beyond direct data-gathering, the survey sent a message to the clients that we valued and needed their input and were keen to avoid the mistakes of the past. Without repeating the survey, our day-to-day work has continued in this mode: clients are encouraged to ask about the rationale for their treatment and to propose changes to the service, and their inputs continue to be valued and influential.



With its client population it's important for the hostel to admit dogs as well as people.

SEVEN BARRIERS AND SEVEN SOLUTIONS

In the responses to the survey we identified seven main barriers to treatment; all the answers were variations on these themes. These are displayed across the bottom half of the article along with the steps we took to overcome them.

As a result of these measures, engagement dramatically improved. Before setting up the clinic, only ten of Endell Street's residents were in treatment with local statutory drug services. Another three were on waiting lists. Over the six months it was piloted, the new clinic quickly filled its 30 slots and for most of the time ran at maximum capacity. Moreover, all but two of 33 clients were still in treatment eight weeks after starting treatment and at 16 weeks, all but three of 22.

During the six months, only four clients were discharged. One left the hostel and was offered several referrals before being detoxified out of treatment. Today they would have been transferred into the mainstream pre-

GOLDEN BULLETS Key points and practice implications

- It is sometimes possible to profitably engage 'treatment resistant' populations in methadone treatment as long as steps are taken address the reasons why they have not previously engaged in treatment.
- Key steps are first to establish contact and then to use this to systematically but sensitively explore their perceptions of the barriers to accessing and remaining in treatment.
- In the case of the Endell Street residents, it was possible to overcome these barriers and provide a methadone prescribing service which engaged patients without compromising clinical safety.
- The main elements were on-site prescribing, an accessible and cooperative pharmacy, flexible attendance requirements, an open and responsive attitude, and acceptance of harm reduction goals short of abstinence from illegal drugs.
- Without being based on the patients' expressed needs, the service might simply have added to their record of failed treatments and to their resistance to trying again.

TOO LONG TO WAIT AND TOO MANY HOOPS

Mainstream services historically require several assessments and appointments before treatment can start. All the clients we asked had found this frustrating, often seeming to receive little in return. Fluctuating motivation means some never start treatment. Others wait, but it makes for a bad start to the therapeutic relationship.

In response we sought to simplify and speed up treatment entry. A substance use worker from the hostel undertakes an initial assessment with potential clients. A familiar face and established advocate, these workers act as a bridge between the hostel and the prescribing service. There is no waiting list and the next available medical assessment (when treatment can start) is never more than five days away from the initial assessment.

At the medical assessment clients provide a urine sample which is tested on-site (and sent to the laboratory for a full drug screen), enabling us to immediately initiate prescribing. All the prescriptions require the client to take the methadone in front of the pharmacist, preventing leakage on to the black market and allowing us to closely monitor adherence to treatment. Take-home doses are given at weekends when the pharmacy is closed. To reduce the risk of leakage on its premises, the hostel purchased safes in which clients store their methadone.

Of course, our capacity is limited – 30 clients. If no spaces are available, no paperwork is done and no promises are made. This reduces frustration at being kept waiting and means that once the process has started it can quickly be completed. Residents who are interested in being treated are encouraged to come and talk to us without obligation.

As a result of these procedures, clients have been able to collect their first dose of methadone within an hour of first seeing the doctor. For them, the lack of a waiting list and the rapid initiation of prescribing are positive aspects of the project.

THERE'S NO POINT – I DON'T WANT TO STOP

Among Endell Street's residents, a history of poor relations and poor outcomes have often undermined the belief that treatment is worthwhile. Part of this is because clients have not been motivated to 'stay clean'. However, they often demonstrate motivation to make smaller changes. By accepting these as valid objectives and achievements, we avoid conflict and yet another 'failure'. This approach is alsao becoming increasingly common in mainstream services. In practice, all Endell Street's clients have made positive changes in their drug use, injecting and criminal behaviours.

We are also able to improve their access to the medical care some badly need. By working closely with the hospital, we can guarantee that after admission they continue to receive an adequate dose of methadone. Reassured in this way, more clients are prepared to attend and to remain on the ward until discharged.

scribing service. Another breached the conditions of his probation and was returned to prison. Two did not collect their methadone for more than four days and were asked to see the doctor to re-engage. The one who did so was no longer using opiates so was inappropriate for methadone.

We can also document improvements in health, reductions in drug use, and the take-up of previously under-used addiction, medical and other services. A fuller report is available on request from the author.[2]

FLEXIBILITY *and* CLINICAL SAFETY

It is important to appreciate what is different about the Endell Street service, but also what has remained the same. The difference is not in the prescribing itself, but in how this is delivered.

Endell Street conforms to the clinical guidelines laid down by UK health departments[3] and to the prescribing policies of the trust's mainstream services: drugs, doses, dispensing and titration procedures are all the same. We have shown that it is possible to maintain these clinical safety safeguards and yet to engage chaotic clients and achieve positive outcomes by providing a client-centred, responsive and welcoming service.

Though they may not be ready to stop using heroin and other illegal drugs, methadone and engagement with treatment benefit the clients in terms of reducing illicit use, injecting, and criminal behaviour and improving health. This kind of service also provides a bridge into mainstream treatment for clients who have been unable to take that step unaided.


MICHAEL HASKEW

Endell Street hostel

THE ENDELL STREET PILOT

The Endell Street Pilot was a joint venture between the St. Mungo's housing charity and the Camden and Islington Mental Health and Social Care NHS Trust.
It main objectives were to:

- engage hostel residents in a methadone prescribing service;
- reduce harm and improve the health of the residents;
- move people into long-term treatment;
- reduce antisocial behaviour in the street.
- prepare people for moving into longer-term accommodation.

IT COULD HAVE BEEN DIFFERENT

Without the survey and the ongoing input of the clients, what might the service have looked like?

Without these we may not have identified the barriers correctly, risking invalid assumptions based on our experiences of other client groups. Where others welcome or can at least work with an enforced structure, for this group too much structure simply creates opportunities for the client to trip up and 'fail'. Other clients at least tolerate waits and assessment and reassessment hurdles, but for this group they become major barriers. Some people come to treatment with a history of at least some success to build on, for the residents of Endell Street, that needs careful nurturing. Most of all perhaps, acknowledging that abstinence is not a realistic goal for this population was key to the service's success. Had we adopted an abstinence goal and applied a more punitive approach ('clean' urines and on-time attendance as conditions of treatment) we would have set the clients up to 'fail' yet again.

REFERENCES

1 See www.mungos.org/projects_sm/endell.shtml.
2 *S. Camden Drug Services and St. Mungo's (Endell Street) HAZ prescribing pilot evaluation*. St. Mungo's and Camden and Islington Mental Health and Social Care Trust, 2004.
3 Department of Health etc. *Drug misuse and dependence – guidelines on clinical management*. HMSO, 1999.

ENDELL STREET

I'LL JUST GET MESSED ABOUT

Injectors who avoid treatment despite their problems often do so because adverse experiences have made them wary of how they will be treated. This was true also of the hostel population, an obstacle we addressed not just in what we offered, but in how it was offered and how they could influence it.

It is important that the service is open, honest and responsive, transparent about why it does what it does but flexible enough to change, positively inviting clients to raise concerns and ask questions. In addition to these everyday communications, clients are also formally involved in clinical governance and service development initiatives. Among these were a mapping exercise specifying what will happen at each step of the treatment process, and a clinical monitoring group including also clinicians, hostel management, and the local residents' association.

I CAN NEVER SEE THEM WHEN I NEED TO

Our clients' lives are characterised by need, unpredictability and crises. Limiting their access to help to set people and set times just doesn't work. So though they all have a named keyworker, they are free to see any member of staff. This means that each client knows all the staff and each staff member knows all the clients. In addition, the hostel's substance use workers are available weekdays from 9am to 5pm. This flexibility makes better use of clinical resources and provides continuity of service for the clients.

I'LL GET THROWN OUT FOR USING ON TOP

Most clients said that continuing to use drugs illegally on top of their prescription had got them discharged from treatment in the past. Expectation that this would eventually happen again deterred treatment entry.

We realised that in this environment, with most of this client group, it was unrealistic to expect illicit drug use to cease altogether. Insisting on this simply becomes another barrier to progress. Instead, we encourage clients to be honest about on-top use so that we can prescribe enough methadone to reduce the need to use heroin. Dropping the abstinence expectation also means that we need very few urine samples. When clients are willing to admit to on-top use, and we know from the pharmacist that they are taking the methadone, little is gained from subjecting them to a procedure they often find degrading. Some samples are required, but we explain why we need them and use them therapeutically rather than punitively.