Development and implementation of early intervention services for young people with psychosis: case study

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Background
The development of early intervention services for young people with first-episode psychosis is a priority internationally.

Aims
To evaluate the development, implementation and impact of existing and newly formed early intervention services in England.

Method
Multiple-case study involving staff, users, carers and commissioners of 14 early intervention services.

Results
Service numbers increased in response to national policy directives. They were still actively working with 90.6% of service users 12 months after inception. They were highly valued by users and carers as providing a personal service that contrasted with previous experiences of care. Tensions between providing a quality service and meeting case-load targets linked to future funding led teams to adopt a series of survival strategies with some unintended consequences.

Conclusions
Early intervention services are highly valued by consumers and engage users effectively after 12 months. Implementation of these services is threatened unless sufficient consistent funding is made available.

Declaration of interest
None.

Psychosis can be a devastating illness. It affects 3.4% of the population over a lifetime.\(^1\) Eighty per cent of first episodes of psychosis occur between the ages of 16 and 30 years. During the past decade, the development of early intervention services for young people with first-episode psychosis has become a priority in a number of countries, including England, Canada, Australia and Scandinavia. This has occurred in response to a shift in resources and focus of care from hospital- to community-based services, user and carer concerns about existing services\(^2\) and evidence that community mental health teams are unable to engage young people effectively or provide specific treatments needed during the early critical period of the illness.\(^3\) A duration of untreated psychosis of 1–2 years\(^4\) and the benefits to patients of reducing this by intervening earlier also support the need for a distinct approach.\(^5,6\)

Early intervention services aim to provide comprehensive, community-based care for young people experiencing early psychosis. In the UK, the Department of Health’s Plan for the National Health Service (NHS)\(^7\) stated that 50 early intervention services for young people with first-episode psychosis aged 14–35 years would be established across England by 2004. Our study aimed to evaluate the development of existing and newly formed early intervention services across the West Midlands of England. It reports the new approaches to care that emphasised access and engagement, the importance of context, the influence of commissioners, strategies for survival in uncertain times and service user and carer views of services.

Method
Participants
A multiple-case study approach was used since this is an effective mechanism both for describing the nature and content of a service initiative (including the context in which it has been developed) and for identifying those factors that may explain its success or failure over a period of time. Moreover, case studies are an excellent methodology for examining interlinked complex social relations as they generate rich descriptive and explanatory accounts of organisational processes, work practices, and the impact of change from the perspective of those being studied, which can provide a source of explanation for wider developments.\(^8,10\) The formative and longitudinal approach also meant we were able to observe the evolution of services, including unanticipated phenomena, and identify and clarify critical issues in service development and implementation.

Semi-structured interviews, each lasting about 1 h, were undertaken with each early intervention service team manager and most team members at three time points: Spring 2004, Autumn 2004 and Spring 2005. In Autumn 2005, interviews were carried out with team managers alone to clarify emerging themes. Mental health leads and commissioners for each of the four strategic health authorities, 17 of 30 primary care trusts and 5 mental health and social care trusts within the region were interviewed at one time point in 2004–5. Early intervention service users and carers were interviewed at one time point in 2005–6. Written documentation such as annual reports and standard operating procedures were also collected. Each service was also asked to complete a 64-item scale with items drawn from national policy implementation guidance\(^11\) that focused on team structure and treatment availability, to explore intervention fidelity.

Standard demographic data were collected on each of the incepted services users during the study period to help describe workload. In view of the importance attached by team members to service engagement, during the first round of interviews we also collected data on the extent of service engagement as recorded in care records at 12 months.
Results

All 14 early intervention services in the West Midlands (population 6 million) participated in the study. Each was at a different stage of development. Two services consisted of a single team manager in place to set the service up and did not actively recruit patients throughout the study period. One team had been established for 10 years and another for 3 years. All other services had been in existence for 6–18 months. The longest established service had the greatest number of whole-time-equivalent staff (n=25). Team size varied but each keyworker was expected to have an active case-load of 15 service users. Ten services adopted a stand-alone team model where team members worked solely with individuals with first-episode psychosis. Two of the twelve active services, both in rural areas and where funding was uncertain, had been in existence for 6–18 months. The longest established service was for the service adopting a hybrid model.

Of the 12 active teams, 9 completed the fidelity scale. Scores ranged from 169 to 231 (mean score of 200 from a possible 256), suggesting good fidelity with policy guidance. The lowest score was for the service adopting a hybrid model.

Of the 62 strategic health authority mental health leads, primary care trust mental health commissioners and mental health trust and social care trust chief executives, 42 (68%) agreed to be interviewed.

Overall, 479 service users were incepted into the 12 active early intervention services over a 2-year period (17–98 per service); 339 (70.7%) were male and 269 (55.9%) were White. A total of 32 service users, purposively sampled on age, gender and ethnicity from 11 of the 12 active services, and 18 carers were interviewed before data saturation was complete. Service users who were interviewed were aged between 15 and 34 (mean age 23 years for both genders), 22 were White British and 12 were female. All carers were parents aged between 35 and 72 years.

Of service users, 90.6% remained engaged at 12 months after inception into the early intervention service: 12 (2.5%) had been discharged, 19 (4.0%) had disengaged and 14 (2.9%) had never engaged fully with the service.

New approaches to care

Engagement was seen as the hallmark of an early intervention service. The foundations were good interpersonal as well as professional skills and focusing on issues relevant to a young clientele. Education and employment issues were priorities for many service users and therefore teams often addressed these before conversations about medication. Accessibility was also a vital element. Many team members used text messages to communicate with services users and deliberately met in low-stigma settings such as the local café.

Eleven early intervention services were multidisciplinary. Most staff shared jobs and responsibilities regardless of professional background. This once again reflected the strong emphasis given to engagement by all teams, which meant that apparently ‘mundane’ tasks such as a visit to the cinema as part of the keyworker role, lifts to the dentist or to the pharmacist were seen as important in keeping service users in contact with the service and helping them cope with everyday things at a point in their life when these could feel impossible to achieve. Psychologists and psychiatrists were, however, the least likely to work in this way since they were perceived as offering profession-specific interventions and were relatively few in number.

Most services actively tried to distance themselves from being seen by users as part of the wider psychiatric system. However, this ‘part of yet different from’ approach led to tensions within some areas with generic community mental health teams. A minority of services, all newly emerging services, felt that some community mental health teams perceived them as elitist, as poaching staff and as having a less intensive workload because of their smaller case-worker:client ratios. Most saw this as a natural response to
change, and appreciated that perhaps some community mental health teams had previously enjoyed working with young people with a first episode of psychosis. Better communication strategies between mental health teams were described as key in helping different teams appreciate their relative strengths. This was also seen as critical in terms of developing exit strategies at the end of the 3 years with the early intervention service back into an inevitably less personal community mental health team service.

All services felt that developmental work was a core part of their team identity and helped to further differentiate them from other mental health services. Two of the more securely financed services ran regular community psychosis detection training and anti-stigma campaigns. Most of the other services focused on developmental work in primary care and schools, where they felt they could make most impact on duration of untreated psychosis within their limited development budget (online supplement 1).

**Importance of context**

A number of demographic factors, particularly relative deprivation and geography, were noted as influencing the implementation of early intervention services. Teams operating in relatively deprived areas were more likely to highlight challenges presented by service users’ multiple complex needs, including poor housing and high local unemployment rates. This created additional work in liaising with a range of services, so that poverty, in a sense, created additional barriers to recovery. Teams in deprived areas were also more likely to report working with ‘hard-to-reach’ groups such as asylum seekers, refugees and migrant communities (online supplement 2). This again led to additional work, not only in terms of accessing good-quality translators who were not understood in translation, but also in creating mutual cultural understanding.

The influence of geography was felt more keenly in rural services, where balancing travel time and face-to-face work with service users was a constant issue. Access to support services was also more limited than in urban areas. Indeed there were far more descriptions of partnership working with the voluntary and community sector within urban teams. A more unexpected finding was the problems created for confidentiality within small and often close-knit rural communities (online supplement 2).

**The influence of commissioners**

Most commissioners, usually senior managers within the organisation that held the funding for developing services, felt they were relatively inexperienced in commissioning early intervention services. Although partnership working across health and social care was seen as vital in developing services, many primary care trust commissioners cited difficulties in making this happen because of poor relationships between different agencies, insufficient resources and recurring organisational restructuring.

The least experienced commissioners described particular problems engaging with child and adolescent mental health services, and voluntary and community sector organisations (online supplement 3).

A significant minority of the primary care trust commissioners described problems in commissioning because they felt the primary care trust placed a low priority on mental health. They described an unexpected feeling of stigma attached to their own role which they felt reduced their potential to develop intra- and inter-organisational relationships and ring-fence budgets for mental health services (online supplement 3).

**Strategies for survival in uncertain times**

The major barrier to developing services from an early intervention service perspective was uncertainty over funding. Commissioner inexperience was frequently commented on by team managers, who felt they had little understanding of the ethos, development and delivery of services, leading to delayed decision-making and problems in securing ongoing funding. Most team managers and particularly those in newly emerging teams, felt commissioners were too focused on ensuring that case-loads of 15 patients per keyworker were met, a target that was tied in part to securing the following year’s funding. Early intervention services responded to the tensions between quality and quantity and uncertainty over funding streams in a number of ways. In the first round of interviews, many team managers described how services relied on staff good will to continue working in such an intensive manner. Team members, however, described the negative effect on morale of working at or beyond capacity for long periods of time to meet targets and ensure further resources were made available. There were also worries about retention of staff and burnout (online supplement 4).

At the second interviews, most team managers talked about a need to reconfigure as a hub and spoke model to save money while attempting to maintain fidelity to the early intervention service framework. During the next 6 months, however, most services managed their workload through tightening age eligibility criteria (one service), discharging service users earlier than the intended 3-year period (three services) or imposing waiting lists (three long-established services). They were aware that these adaptations rendered them non-compliant with Department of Health policy implementation guidance and, in the case of invoking waiting lists, was recognised as inimical to early intervention. All but two teams also spent less time on developmental work in the community than they would have liked. During the final round of data collection, no service operated a waiting list and most were trying to find different ways to continue by, for example, working in partnership with other organisations and finding alternative sources of additional funding (online supplement 4).

**Service user and carer views**

Almost all service users were anxious at the prospect of referral to a mental health service but described the reality of engaging with early intervention services as positive. Fourteen of the service users who were interviewed were initially referred after an in-patient admission on a psychiatric ward. These service users compared their experiences of hospital-based care and early intervention services, and described the former as places where they were treated like children, not listened to, were unable to influence decisions and where staff constantly changed. Early intervention services, in contrast, were staffed by people who were ‘consistent’, ‘knew what they were doing’, ‘cared’, ‘weren’t pushy but listened’, and were ‘very helpful and gave lots of information’ (online supplement 5).

Many noted that they themselves had held negative views of people with mental illness before their own episode of psychosis and described being ashamed and embarrassed initially about their own diagnosis. The early intervention services had helped by giving them information that addressed their stereotypes, reduced their fears about the future and increased their self-confidence so they were more able to talk to friends and employers about their illness.

Most carers were also happy with the care provided by the early intervention services, often comparing them positively with services they had previously been in contact with. They highlighted the availability of team members out of hours and the hope for recovery they were given. Many mourned their
own loss of independence since the diagnosis and valued the extra
time and support offered to them throughout the illness. Some felt
the timely and high-quality interventions had saved lives (online
supplement 5).

Discussion

This in-depth longitudinal study tracked changes in early inter-
vention services over time to gain multiple views of com-
misioning, delivering and experiencing such services. It provides
a series of complex contextualised unfolding stories that may hold
lessons for the implementation and development of other health
services nationally and internationally. It shows that the number
of services has increased in response to policy directives; that they
include the key structural elements required by national early inter-
vention service implementation guidance; can effectively engage
service users over a 12-month period; and are highly valued by
service users and carers. However, there are tensions between
providing a quality service and meeting case-load targets linked to
future funding and gaps between stated policy and actual practice.

Early intervention services managed these through a variety of
survival strategies. The situation appeared to be exacerbated by a
lack of experience and understanding of the need for consistent
funding at commissioner level.

We had expected more negative comments from users and
carers about the high and sustained intensity of the services and
the possible sense of intrusion from the community, predom-
inantly home-based, intervention. None had yet experienced the
step down in care around discharge, which may conceivably be
experienced as a relief and a threat. This is an important future
question and challenge for the policy guidance.

Strengths and weaknesses in relation to other
studies

Two trials have demonstrated that integrated intensive services at
an early stage of psychosis can lead to improved clinical outcomes,
including fewer psychotic symptoms14 and lower relapse rates.15
The findings add to these and other previous studies on early
intervention services, by helping to explain the elements and
methods that underpin their success, including the importance
of developing a youth-friendly service with a recovery focus.16
Engagement with and advocacy for service users have also been
described as critical issues in developing early intervention
services.17 A lack of understanding and experience at commissioner
level are recognised barriers to good commissioning in a range of
healthcare contexts.18

Few previous studies of early intervention services have
reported such high service engagement at 12 months. Indeed
the UK trial of early intervention reported contact rates at 18
months with community mental health teams of 59%.15 The
positive views of service users and carers provide a contrast with
the negative views in a national survey of users with first-episode
psychosis and their carers in 2002 and more recent Scottish data
on the needs of and service provision for young people with
adolescent-onset first-episode psychosis receiving care from
mainstream mental health services.19

Limitations

Study limitations include the method of approaching service users
and carers. Although the research team purposively selected
service users to be invited to take part in an interview, the
keyworkers in each team then approached them to gain initial
consent. This approach might potentially have excluded the
recruitment of users with more critical opinions. We also only
had ethical approval to interview carers if services users gave their
consent, which, once again, may have excluded carers with the
most strongly held or critical opinions. Service engagement was
assessed through looking at care records at 12 months to see
how many service users were still in active weekly contact with
their keyworker, rather than through a service-user-completed
engagement scale. We did not collect data on the views of
community mental health team members on early intervention
services which, with hindsight, could have provided interesting
perspectives on perceptions of elitism noted by some of the
interviewees. Qualitative methods enabled a more in-depth
understanding of the challenges faced by different teams. The
generalisability of the project findings derives not from the
representativeness of the sample but from the concepts that are
relevant to other settings and patient groups.20

Implications for clinicians and policy-makers

Early intervention services now have a stronger evidence base in
terms of effectiveness than all other recent service-level changes
in mental healthcare, including assertive community treatment21
and home treatment services.22 There is, however, still scepticism
about service implementation from parts of the mental health
system.23 This in-depth study may help to allay some of this
criticism by demonstrating the evolutionary and generalisable
mechanisms, rooted in good interpersonal relationships, commit-
ment and flexibility in adversity, that underpin the success of early
intervention.

In healthcare systems where patient choice and satisfaction are
increasingly recognised as important,24 the positive views of early
intervention services from service users and carers, particularly in
comparison with views of more traditional generic or hospital-
based services, are encouraging for policy-makers, funders and
clinicians. This study of routine service provision, outside of the
necessarily controlled setting of a trial, has also demonstrated that
early intervention services are able to engage young people with
first-episode psychosis very effectively. Other mental health teams
may find the engagement strategies and new approaches to care
helpful in informing their own service delivery plans.

However, the tensions created for staff in having to meet
performance targets related to case-loads, as well as pursuing
developmental work in the community and supporting often
distressed family members, led to the development of a series of
pragmatic survival strategies without knowing the consequences
for user outcomes. Although most teams found a middle ground
over time, there were inevitable consequences for team morale and
patient care, including the oxymoron of a waiting list for an early
intervention service, as the teams struggled to balance differing
pressures and demands. Early intervention services are not unique
in experiencing such tensions and there are generic implications
for service planners about the unintended consequences of
performance targets in a healthcare setting. Finally, consistent
funding that recognises the importance of developmental as well
as case-load work is required to ensure the continued
implementation of services across England.
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References

17 Peck E, Greatley A. Mental Health Priorities for Primary Care. King’s Fund Centre for Mental Health Services Development, 1999.
New approaches to care

‘On the one hand we’ve been recruited because we are highly qualified, highly experienced people, but a lot of the job is running around. Sometimes it’s being a taxi service really as well.’

(Approved social worker, team A)

‘Engagement to me is about availability as much as anything. OK, if you’re going out to the person’s house, they don’t let me in, but leave a note saying you’ve called, put your telephone number on, perhaps you can speak to them on the phone initially, things like that. Perhaps you can get someone they know to come along. OK they might reject you, but you keep going back, really, not pestering, just showing that you are available, that you are genuinely concerned. A person that you have a good rapport with and then the rapport wanes, you stick with it through thick and thin really, consistency. When they don’t want help that’s fine, just let them know that you’re still there and then when they’re ready to come back to you, they often do, really. Initially engagement to me is about posing as little threat as possible.’

(Community psychiatric nurse, team D)

‘It’s important to keep your distance from the community health teams while maintaining good links. You should see yourself as offering an alternative to traditional psychiatry – see yourself as a young person’s community-based “something else” and not just an off-shoot of the local psychiatric service.’

(Occupational therapist, team B)

‘I think the worst thing for the client is the level of input they will have after they leave us. There is no way that community mental health teams can offer the same level of service as we do. Also, if there is a relapse they don’t have the capacity to respond as quickly as us – like the same day or the one after.’

(Community psychiatric nurse, team C)

‘Part of the ethos of early intervention is not just having the team and the early intervention service; it’s about health promotion, breaking down stigma, developing networks. So some team members might have, as part of their role, work in schools, some might be liaising with primary care, might be a case of doing sessions in surgeries and that sort of stuff.’

(Community psychiatric nurse, team L)
Online supplement 2

The importance of context

“We’ve got six or seven people from Afghanistan with psychosis and our understanding of that culture is not good and so the service we provide is not as good because our experience is with people from Black and Asian communities.”

(Occupational therapist, team C)

“The geography causes me real problems because it can be 90 miles to get to somebody and I don’t necessarily know if the resources that would help me are available in a little village.”

(Community psychiatric nurse, team A)

“There is one young man in the village who has developed a psychotic illness. He is so talked about, so stigmatised, he stands out so much that the demographic of the area causes huge problems for him and cuts him off from a lot of resources that might otherwise be available to him.”

(Community psychiatric nurse, team J)
Views of commissioners

'I think from a professional viewpoint it worries me that I don’t have a mentor for this new role as it is a responsible position. I have plenty of experience in clinical things, as a provider, albeit none in mental health, but I’m actually doing this as a commissioner which is totally different.'

(Mental health commissioner, primary care trust 4)

'I think I can also say that the local planning group in this area haven’t been particularly pro-active, particularly because of the large number of organisational changes that have taken place recently. So it’s [referring to mental health planning for children] been left in a void for a while.'

(Planning officer, child and adolescent mental health services executive 15)

'I have come across health service managers that still don’t want to have to attend to, or prefer not to be involved with, mental health. They just don’t want to know. I get a feeling I don’t get the same things as some of my other colleagues, but I don’t know if that’s the truth. It’s interesting; a remark somebody made when I started on the first day: “You’re braver!”'

(Mental health commissioner, primary care trust 4)
Strategies for survival in uncertain times

“The funding was lost last year. It’s restricted this year; it’s half of what we expected. And half of what is in the development plan proposal I put in – two staff a year over a 3-year period to get a team of six.”

(Interview 1: psychologist team manager, team J)

“...we will go the extra mile, but we seem to be going the extra 10 miles at the moment and I know none of us complain about that, but in realistic terms we can only do that for so long before we burn out. And that’s my biggest worry. Because we so want to help young people and do what we can when we can, and we will just burn out.”

(Interview 1: community psychiatric nurse team manager, team C)

“Apart from the morale and retention issues, I think clinically we will have to fold. I think we will have to disperse into separate community mental health teams because we can’t continue to absorb acutely ill people and have 12–16 of them on the case-load.”

(Interview 2: community psychiatric nurse team manager, team D)

“I don't see demand shrinking and I don't see the service necessarily growing either. I think the way we deal with that is trying to be strict about our entrance criteria and also I think we’re going to have to be quite strict about not hanging onto patients once their 3 years are up, because there is a temptation to think ‘oh because we've done so well it's a shame to discharge them now’ particularly if you feel you may be discharging them to an inferior service.”

(Interview 3: community psychiatric nurse team manager, team J)

“We need to go out to schools, colleges and to youth clubs raising the profile of early intervention and the awareness of problems. We could even write an article in the local paper and things. All these will bring people forward at least for an assessment or screening in terms of early psychosis. We know that we need to do it at some point but it's about getting the balance right. I'm not sure that the primary care trust understands how much time developmental work takes.”

(Interview 3: occupational therapist, team B)

“We've got a project that's due to open next year, early next year by January, which will be a multi-agency youth service . . . that will be funded by a number of different funding streams, have strong youth focus, be easy to access so young people can walk in and just hopefully get help . . . I think that's where it will go.”

(Interview 4: community psychiatric nurse, team manager, team F)
Views of service users and carers

'I didn’t know whom I was going to meet. I thought they were taking no notice of what I was saying and making decisions without me... Sometimes it made me really angry and I was thinking “I know what I am saying and doing and they don’t listen to me”.

(Service user, team J)

'Well, I weren’t too happy because what I found is that the doctors keep leaving and we keep getting new ones, so you have to start from the beginning. I actually did a letter of complaint and they wrote saying they were looking into it.

(Service user, team C)

'They done everything they can and the medication gives me the best quality of life that I have had and almost normal quality of life. The other things that I have done have helped me to grow in confidence and to manage and cope with the voices and visions.

(Service user, team A)

'I found it very helpful looking at my psychotic periods and just general mental health problems over the 18 months prior to being here. I came away with an understanding in the last month where I have wrote down my experiences again. I’ve used [keyworker] to talk over things in understanding and feeling less ashamed which is what I was feeling with having a mental health problem, that it’s something very shameful and embarrassing, but now it’s given me confidence in that area.

(Service user, team G)

'[Service user] was a classic case and there were various percentages flashing around but we seized on one that was, I don’t know, 30% that recovered and never relapsed, that there was a good possibility that she would recover and not relapse again, so that gave us hope among all the doom and gloom.

(Dad, team J)

'There was one day when everything was really difficult and I can’t remember whether [name removed] rang them or I rang them, but they stayed behind at five o’clock and saw us and they said, “we will stay as long as you need us to stay.” There was no sort of pressure.

(Mum, team C)

'It’s very refreshing because I felt like I was listened to, and there was honesty, and quite an unusual way of working when they actually seemed to care about me, not just [user]. My well-being was as important as [user]’s, which to me did make a difference because it was almost like I needed healing too, because I was so damaged by what the system had done to us, in a way.

(Mum, team E)

'I can’t praise them enough and the level of care you know... She doesn’t have to get on any public transport. They personally come and fetch her in a car from the door. Take her bowling, to the cinema, to the gym. She gets to be with other clients, other workers in the service and then she gets dropped straight back off at the door. The care is there from the minute she leaves the house “til when she comes back.”

(Mum, team D)

'We think that if it wasn’t for the early intervention team, [user] wouldn’t be here now. She was adamant that she was going to kill herself. She didn’t want to be here. She said she was hurting too much. The team has made so much difference to us as a family simply because of the understanding they have about the problems we are experiencing.

(Mum, team B)
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References
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