EDEN: Evaluating the development and impact of Early Intervention Services (EISs) in the West Midlands

---

A Report for the NHS Service Delivery and Organisation National R & D Programme

July 2006

Prepared by

Professor Max Birchwood

Professor Stirling Bryan

Mrs Nicola Jones-Morris

Mr Billingsley Kaambwa

Professor Helen Lester

Ms Julie Richards

Dr Helen Rogers

Ms Namita Sirvastava

Dr Effy Tzemou

Address for correspondence

Professor Helen Lester

National Primary Care Research and Development Centre
5th Floor Williamson Building
Oxford Road
Manchester
M139PL

Executive summary

Introduction

The EDEN study was funded by the NCCSDO Programme of Research on Models of Service Delivery and Organisation. It ran for three years from July 2003 with data collection active from March 2004 to February 2006.

Aims and objectives

EDEN aimed to evaluate the implementation and impact of EISs across the West Midlands with diverse socio-demographic, geographical and National Health Service (NHS) structures and provide important information to help ensure services are effective and sensitive to the needs of young people.

Methodology

Conceptual framework

This study adopted both a formative and summative evaluation framework within a multi-case study methodology that included qualitative and quantitative data collection and analysis.

Location

Each of the 14 EISs in the West Midlands decided to participate. Twelve services actively incepted service users during the study time frame.

Data collection and analysis

Formative aspect

Semi-structured interviews were undertaken with 42 Strategic Health Authority, Primary Care Trust and Mental Health Trust executives and 50 service users and carers, and 162 interviews were conducted during the two-year study period with EIS Leads and team members.

Summative aspect

Audit data were collected from the case notes of 479 service users incepted into 12 active EISs during the period from 1st September 2003 until 31st August 2005. The data collection start date was six months prior to the collection of formative data in recognition of the time it can take to engage service users into the EIS. Regression modelling was used to explore the

variability in duration of untreated psychosis (DUP) and use of a section of the Mental Health Act (1983).

Findings and discussion

Objective 1: To provide information on key aspects of EIS development and delivery to maximise the effectiveness of emerging services

Aims and visions of the services

There was little variation between the teams in terms of their overall aims and objectives since all EISs delivered an holistic approach to first episode psychosis (FEP) which focused on the need to work with service users using a bio-psycho-social approach.

There was, however, less consistency in terms of referral pathways into the teams. Most adopted an 'open system', accepting referrals from virtually any source, but a significant minority took a more restricted approach where the source was either another mental health team or primary care.

Issues of access

Access was a key issue and encompassed a number of different but related concepts such as geographical and temporal access. The influence of stigma was also noted as important.

Youth sensitivity and engagement

Engagement was perceived as critical. All services achieved high levels of sustained service user engagement. At 12 months, 434 (90.6%) of people were still engaged. Service accessibility, team members' perseverance, creativity and youth sensitivity were considered to be the key factors that facilitated engagement. For a minority of services, the significant youth focus led to the employment of specific Youth and Community Workers.

Issues of stigma and stereotyping

Considerable emphasis was placed on combating issues of stigma, stereotyping and prejudice.

Many service users had preconceived ideas about mental health problems and their treatment which, more often than not, had been fuelled by inappropriate media reporting. Dealing which such feelings and concerns was said to be an integral part of the work undertaken with the service user as part of the recovery strategy.

Usefulness of EISs from the perspectives of users and carers

All service users reported that EIS involvement had been positive. They spoke of help with medication, relapse prevention, the provision of good support and consequently, strong relationships with their key workers, help with motivation in order to facilitate a return to education and employment, and support to re-establish self-esteem and self-confidence.

The majority of carers reported high degrees of satisfaction with the services provided. Key aspects for them included the availability of staff, levels of reassurance, comprehensive support and a strong focus on building the confidence and self-esteem of service users.

Objective 2: To identify key components of successful service configurations and their adaptation in different geographical and socio-economic settings and understand how local factors facilitate or hinder EIS development

Ten of the 12 EISs adopted a stand-alone service configuration and there was good evidence to suggest that this was the preferred configuration of EIS team members. However, the degree to which this has been feasible was said to be dependant on the willingness of commissioners to invest the level of resources needed to fund a stand-alone service, particularly in rural or semi-rural areas.

Alongside geographic location, a number of other demographic factors, notably cultural characteristics, relative deprivation and gender, were said to present challenges within the context of service development and delivery.

Hindrances

There was strong evidence to suggest that under-funding was a key factor in determining the stability and suitability of EISs. In a minority of services, where funding was secure, a predominantly proactive rather reactive service had developed. However, for the majority of EISs, funding was perceived as insecure which meant that planned activities were governed by a 'stop-start' approach that gave rise to feelings of frustration and low staff morale. Furthermore, several EISs experienced delays in receiving confirmation (or otherwise) of increased funding which made strategic planning more difficult. Under-resourcing placed great pressure on EISs and their staff and many reached capacity within their first year, compromising the aim of EISs to provide all young people with a FEP with consistent support over three years. In some cases, waiting lists developed thus leading to later intervention.

Second, for the minority of relatively well-financed services, developmental and promotional work had been identified as an integral part of establishing an effective EIS. However, for the majority of EISs, this was not taken into account in the initial budget setting stage, which led to teams having to prioritise what little time they had for developmental work in a way that ensured positive outcomes. Wider developmental work in the community or

with user and carer groups was not possible for most EISs because of staff capacity issues and tensions created by the need to manage case load and hit targets to secure future funding.

Third, the majority of EISs experienced problems in recruiting or retaining team members, particularly Social Workers.

Fourth, a perceived hindrance was the lack of a dedicated psychiatrist in most of the teams. Only five teams had a dedicated post. This was described as exacerbated by delays in securing agreement on the content of the job description, a lack of funding and an apparent disinterest in vacant posts.

Fifth, not all teams felt that their office base was conducive to engaging with young people during their first experience of mental health services. There was a strong sense that, from the outset, little thought had gone into identifying suitable accommodation that was non-stigmatising, welcoming and accessible.

Facilitators

Five key facilitators were identified. Ownership and understanding of the role and purpose of EISs by those involved in strategic and operational decision-making within the locality was considered important.

Second, at a team or peer level, two significant facilitators were identified - the experience and attitudes of individual team members and the development of a collaborative and cohesive team ethos. Personal attributes of team members or potential team members were rated more highly than qualifications since cohesiveness and dedication to the principles of EISs were thought to be borne out by employing the 'right people for the job', 'having a wide-range of experiences and skills' and 'the energy to make something you believe in work'.

Third, the presence of 'local champions' in terms of EI Leads was considered to be a significant factor during the early stage of development. There was a strong sense that such individuals had both the knowledge and skills to influence those who occupied senior management positions and were thus instrumental and active in strategic decision-making processes. However, as time went on, the dependence on 'local champions' appeared to change or in some respects diminish since team members, themselves, felt equipped to take on this role as their confidence in working with FEP increased.

Fourth, all the EISs found the opportunity to network with colleagues extremely beneficial.

Fifth, there was a strong sense that working with other agencies and organisations both within and outside of the mental health domain had generated positive outcomes, not just for the team members in terms of skill or knowledge development, but also for service users**.**

Objective 3: To understand the effect of structural relationships between Primary Care Trusts, Mental

Health Trusts and Social Care Trusts on commissioning and/or providing EISs and identify lessons for future development of EISs within a whole-systems approach to mental health

Four key themes emerged. Less experienced commissioners seemed unable to engage fully with other potentially key groups such as service users and carers and other statutory and non-statutory organisations.

Organisational culture also appeared important. A number of PCT commissioners suggested that poor relationships between different agencies involved in developing EISs were due to differences in organisational culture and structure and a lack of commitment to partnership working. However, such difficulties were said to be frequently underpinned by insufficient resources or recent organisational restructuring.

A significant number of the PCT commissioners described how they felt that there was a degree of stigma attached to their roles as commissioners for mental health. This had an effect on their ability to carry out their commissioning role by reducing their potential to develop intra- and inter-organisational relationships.

Structural relationships between organisations and implementation issues also had an impact on commissioning EISs. Generally the relationship between the SHAs, PCTs, Mental Health Trusts or Social Care Trusts was perceived as hierarchical; policies were formulated at a national level, interpreted at the PCT level and implemented by the EISs at 'ground level'. Some PCT executives reflected that in their opinion this was the most satisfactory way of introducing new policy since they felt that the top-down approach gave them the element of control required for successful implementation of the new and potentially complex policy. Tensions however, occasionally arose with the 'top down' approach. Some PCT commissioners were trying to develop EI policy from the 'bottom up', adapting and responding to their local environment and patients' ideas, which were not always in concordance with national policy.

Objective 4: To provide information on the relationship between different service configurations, fidelity to national EIS guidance and key pre-defined outcomes such as duration of untreated psychosis (DUP)

Regression modelling was used to explore the variability in DUP and use of a section of the Mental Health Act (1983). Since all but two of the teams were stand-alone in nature, and neither of these returned the fidelity scale that was a key part of the model, we were unable to explore the relationship between service configuration and key outcomes.

DUP model

Our results showed no significant association between age and gender and DUP or with employment status, however the trend in the employment variable does show that longer DUP was associated with unemployment, in line with results from other studies.

Sectioning model

In variance with other studies we found a significant positive relationship between being sectioned and the involvement of a GP or primary care team. These results should, however, be viewed in the context of only 13% of service users entering EISs via this route. This proportion is much smaller and may therefore not be as representative as that in other studies.

Objective 5: To explore reasons for variation in the costs associated with the delivery of EISs

Throughout the four rounds of data collection, availability of resources was consistently mentioned as the greatest challenge to implementing EISs. This led to sensitively in providing information to the research team about resources. During the final round of data collection, when we had expected to collect detailed cost data, all of the EISs were engaged in what was frequently described as 'delicate negotiations' with their respective Trusts and PCTs and were therefore reluctant to disclose any information about their actual or proposed budgets.

Implications

Implications at a local level

1. **There needs to be greater clarity and transparency over funding mechanisms**

Perhaps the most important implication both locally and indeed nationally is the need for greater clarity and transparency over funding mechanisms for EISs. There is also a need for services to be assured about the recurring nature of funding to help plan service development at a strategic level and the balance of case work and developmental work.

2. **PCT expectations need to be clear and linked to funding streams**

There appears to be a significant emphasis by PCTs and SHAs on achieving targets, particularly in terms of caseloads. This, however, can create tensions at a team level between the quality of the service and the quantity (number) of young people accepted into the service. Clarity over the expectations of all parties, linked to clear funding streams, is required to enable EISs to pursue both clinical and developmental work.

3. **Service user and carer involvement needs to be encouraged more proactively**

There is little evidence of service user or carer involvement in most of the EISs. This is related to lack of time for developmental work and also to some extent by service users' desire to recover and move on rather than necessarily making a 'career' as a mental health service user. However, a minority of teams have successfully engaged a service user as a team member and this appeared to have a positive effect on team ethos.

4. Tensions of genericism within a specialist services need to be recognised

All except one team were multi-disciplinary in nature. Teams were therefore able to provide a range of skills to service users and carers. However there is a need to recognise tensions that can occur when encouraging genericism within the team yet also valuing the specialist skills that all team members bring.

5. **Better communication strategies are required between teams**

Good communication strategies with local mental health teams appear to be key. This is important in terms of developing entry and exit strategies into EISs and also for developing good relationships between different parts of the wider mental health system.

6. PCT commissioners need a more in depth understanding of EISs

At a PCT level, commissioners need to develop a greater understanding of how EISs work. This requires greater stability at a PCT level in terms of personnel and the appointment of commissioners who understand the intricacies of mental health

7. PCT commissioners need to understand the intricacies of partnership working

The significant policy emphasis on joint working between different sectors within the NHS (e.g. CAMHS and EIS), health and social care, health and the voluntary sector and on greater public involvement in service design and delivery mean that understanding partnership working issues will become more important in commissioning EISs in future.

8. PCT commissioners need to recognise the stigma of mental illness

The stigma of mental health may affect PCT opinions on the importance of commissioning good quality mental health services.

9. Clearer lines of communication are required between EISs and CAMHSs

Greater clarity is required about the relationship, roles and responsibilities between CAMHSs and EISs, particularly as some of the services move towards developing a much stronger youth focus through employing specific youth workers.

10. Excellent service engagement strategies could be generalised across England

Service engagement was uniformly excellent across all services. This suggests that other EISs could learn from the experience in the West Midlands in terms of developing successful engagement strategies.

11. Developmental work in the community requires greater focus and funding

The mean DUP across services in the West Midlands is 16 weeks. Although teams frequently said that they had a little time for developmental work, the fact that the DUP is so much lower than many other reported DUPs suggests that the developmental work and community connections described by teams may be having an influence in raising awareness of early symptoms and signs of psychosis.

Implications at a national level

These recommendations need to be tempered by the knowledge that they are based on data collected from one geographical area of England.

1. Better communication about the value of EISs is required at a national level

There is a need to communicate the value of EISs at a national level so that the wider mental health community understands their roles, responsibilities and value.

2. Flexibility to the PIG is required to take different locality needs into account

Slavish adherence to the Policy Implementation Guide at a national level may not fit the increasing move towards a youth service in some areas. Although the mean score on the fidelity scale was 200, suggesting a good fit with PIG for most services, flexibility may be required in future as services reshape in response to funding constraints, user preference and the emerging evidence base.

3. Funding for EISs needs to take into account local needs

Service commissioners need to appreciate the flexibility required in terms of EIS shape, form and function to enable the development of locally sensitive and appropriate EISs depending on whether the EIS is an a rural area, the availability of voluntary and community sector services and the socio-economic characteristics of the client group.

4. The EIS recovery focus needs to be championed beyond the immediate service

The importance of a recovery focus was an important issue in interviews with EIS team members, users and carers.

Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health

Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene and Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk