The service needs of mothers with schizophrenia: a qualitative study of perinatal psychiatric and antenatal workers

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Received 26 October 2007; accepted 3 December 2007

Abstract

Objective: The study sought to (1) understand the perspectives of perinatal psychiatric and antenatal health service workers on the service and support needs of mothers with schizophrenia; (2) obtain their views on the feasibility and potential effectiveness of a proposed parenting intervention tailored for this group.

Method: Twenty-eight perinatal psychiatry and antenatal service workers were interviewed using a semi-structured methodology, and anonymised verbatim transcripts analysed for content themes.

Results: Many respondents felt that women with schizophrenia received insufficient postnatal support. Perceived needs were: support with adjustment/coping; parenting skills and sensitivity training; maintaining mental health; continuity of care and community support; and encouraging bonding. Service integration/continuity and social stigma were recurring themes that impacted on recommendations, such as the need for interdisciplinary communication and mental health education for midwives. The parenting program was generally well received, although many raised concerns regarding patient involvement and specific intervention characteristics.

Conclusion: The views of health workers are a valuable complement to the service user perspective. They highlight the needs of this high-risk group in their transition to motherhood, and how they might be met, as well as a need for staff training so that parenting interventions are better understood as positive prevention work.

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Keywords: Service needs; Mothers with schizophrenia; Perinatal psychiatry and antenatal service workers

1. Introduction

Mothers with severe mental illness commonly describe parenthood as a rewarding experience [1–4] and generally care for their children adequately [5,6]. However, the demands of parenting while managing a mental illness can be challenging [1–4,7–9]. Empirical studies suggest that mothers with schizophrenia are particularly vulnerable to difficulties with parenting [10] and interacting sensitively with their infants [11–14], leading to risk of infants developing insecure attachment [15,16], or being removed to care [10,17]. Studies suggest that whether children remain with the mother depends largely on the quality of support given by her partner and others [10], and on the presence of frequent and multiple supports [2]; yet mothers with schizophrenia are more likely than mothers with other mental illness to lack support and live in impoverished social conditions [10].

Many women with severe mental illness report being dissatisfied with the mental health care they receive [1,3,4]. In qualitative studies, they describe their service needs to include specialized parenting groups, family education, family meetings with health professionals, links with community agencies, and provision for their children [1,3]. Several countries in Europe and Australasia have set up designated mother and baby units (MBUs), which allow joint mother and infant admissions [18], but whether they meet the mother and child’s needs beyond acute psychiatric treatment has been little studied [18,19]. Localised parenting programs offer little empirical evidence for this group [20–22].

The views of healthcare professionals who work with mothers with mental disorder provide a different perspective on service need and on the obstacles this group may experience in accessing care. In one US study, case managers
reported a lack of adequate support and resources for mothers with mental illness and expressed serious concerns for their children [4]. An Australian study of service providers highlighted poor communication between agencies and a lack of appropriate community resources [23]. In another Australian study, mental health workers expressed concerns that discussing parenting and child-related issues might disrupt the patient–carer relationship [24]. They report that working with patients’ parenting is impeded by patients not identifying their illness as a problem for their children or denying that they have a mental health problem.

This qualitative study was conducted, in part, to inform the development of The BABIES Project, a parenting intervention program tailored for mothers with schizophrenia. Accumulating evidence suggests that the infant–mother attachment and relational difficulties are an important mechanism through which children of mothers with schizophrenia are vulnerable to poor developmental and clinical outcomes [25]. We planned to develop a behaviourally based program aimed to improve maternal sensitivity commencing at 6 months postpartum using positive parenting and video-feedback techniques, which have been shown to be effective in other high-risk groups [22,26]. The personalised intervention was designed to be delivered by an independent ‘guider’ in six weekly 1.5-h sessions. It was therefore important to have the co-operation and support of healthcare workers, who are in frequent contact with these women, to encourage patient participation and confidence in the program.

We interviewed hospital staff working within antenatal services and perinatal psychiatry, two main points of contact for these women in which support services could be developed. The study aimed to explore the perspectives of hospital workers on (1) the service needs of mothers with schizophrenia; and (2) the feasibility and potential effectiveness of the proposed intervention program for mothers with schizophrenia.

2. Method
2.1. Design and participants

A primarily qualitative interview methodology was employed to explore the full range of the workers’ perspectives and experiences. The study was part of the development phase of a larger project examining the feasibility of a tailored parenting program for mothers with schizophrenia and was approved by local research ethics committees. Health care workers employed by the National Health Service were approached to participate at three sites in the northwest of England in Manchester (MBU; antenatal clinic) and Liverpool (antenatal clinic).

2.2. Data collection

Semi-structured interviews were conducted and audio-taped between November 2006 and March 2007 by a trained university researcher employed independently from services. To obtain a purposive sample, the researcher liaised with the clinic or ward manager at each site to approach all workers who potentially work with expectant and/or postnatal mothers with schizophrenia (i.e., at the MBU or within specialist mental health antenatal clinic times). Following obtaining informed consent, interviews were undertaken at the respondent’s workplace. A sequence of predetermined questions invited closed- and (mainly) open-ended responses, with probe questions to prompt elaboration on the initial response. Leading questions were avoided. Topics were established to cover all aspects of the aims of our study, which explored:

- Current support and services for mothers with schizophrenia
- The service and support needs of mothers with schizophrenia and their infants
- Reasons underlying a lack of postnatal support
- Recommendations to improve services and support
- Opinions on the feasibility and effectiveness of the planned parenting program and other intervention methods/characteristics

Participants were told that quotations from the interviews may be used in reports from the study, but that individual participants would remain anonymous.

2.3. Data analysis

The interviewer analysed anonymised verbatim transcripts of the interviews using thematic analysis. Thematic analysis is a qualitative technique increasingly used in medicine to gain insight into the user perspective, such as the views and experiences of women with severe mental illness [1–7] and their service providers [4,24]. After reading the transcripts several times, a coding frame was developed for each of the main topics in the interview, which were determined by the study aims. In each coding frame, an index of codes resulted from grouping together responses through an iterative process in an attempt to bring similar or related ideas together to develop sub-themes. Each coding frame was then elaborated and modified as new sub-themes emerged in the course of the analysis. Similar sub-themes were grouped together to attain the minimum number of themes that adequately capture all the data. The interviewer’s analysis showed good agreement with an independent researcher’s analysis, which was performed to monitor potential bias from the interviewer. Direct quotations were taken to support each identified theme.

3. Results

The 28 workers who were approached to participate agreed to be interviewed, although not all workers at each study site were approached. The sample represents a range of occupations, although most were midwives and registered
mental nurses (Table 1). In the UK, a midwife is usually the first and main contact for the expectant mother during her pregnancy, and throughout labour and the postnatal period. Registered mental nurses, in this study, worked in the community \((n=1)\) or inpatient facilities \((n=6)\). The nursery nurses in this study are involved in the practical care of and play with infants at the MBU. Participants worked with women with schizophrenia in either the antepartum or postpartum period. The amount of contact they had with such patients varied, as did the length of their responses (interviews ranged from 15 to 30 min). All but one participant had worked directly with this group, and nearly half of the sample had regular contact (i.e., more often than once a month). Of those workers who had occasional, rare or no contact with pregnant or postnatal women with schizophrenia, 10 were midwives and 1 was an obstetric consultant.

### 3.1. Existing support

Twenty-one of 28 participants reported that they gave one-to-one support or advice to schizophrenia patients, which could be grouped into six themes (sub-themes in parentheses): appropriate referral \((n=14)\); general, mental health team, specialist midwife, health visitor, psychiatrist); advice on practical infant care \((n=12)\); routines, problem solving, coping skills); obtaining information for planning \((n=8)\); obtaining clinical history, planning care after delivery); education on their mental illness \((n=7)\); insight into illness, understanding medication); enhancement of maternal sensitivity \((n=7)\); and providing information and reassurance \((n=5)\); available resources, information to make an informed decision, reassurance about illness and stigma). Postnatal workers focused on the enhancement of maternal sensitivity, such as encouraging mothers to communicate vocally with their infants. They often provided advice to mothers and behaviours for modelling, although not as part of a structured program.

Antenatal workers’ responses focused on referral, planning and providing information: “We give a lot of reassurance that they’re not going to be ostracised. Their big concern with any woman with [a] mental problem is that the baby is going to be removed...We often have a lot of women who will come here for their antenatal care rather than go to the community, ’cause they’ve seen you and they recognise you...and ’she didn’t judge me’ and I think that’s a really big one.” (P19, registered mental nurse)

Thirteen participants believed that women with schizophrenia received insufficient support in the postpartum period, including all postpartum (MBU) workers. Seven respondents felt that ignorance and social stigma were responsible for such insufficient support, referring to ignorance within services, a lack of mental health training, or the social stigma attached to schizophrenia and parenting: “I think, on behalf of services which have given support, is there’s ignorance about mental illness and how mental illness works...People are ill in phases...If they’re distracted and...preoccupied, they’re not going to be able to do it well and take on information or thought blocking. But in actual fact, when that goes, they’re back to normal like you and me” (P1, registered mental nurse). Insufficient postnatal support was also attributed to a lack of resources \((n=7)\); time constraints, lack of staff, poor availability of services), a lack of integrated care \((n=3)\), inconsistent provision dependent on geographical area \((n=6)\), and whether patients are already known to services \((n=3)\).

Twelve participants felt that this group received sufficient postpartum support, five of whom worked regularly with antepostnatal women with schizophrenia and four of whom rarely worked directly with this group. Some made reference to the mental health service and (for the MBU) inpatient facilities their service provided. Three antenatal workers were unsure and admitted to knowing little about postpartum services: “My experience is very limited about what support they receive. As far as I know, the majority would, but obviously I'm sure there's a few that slip through.” (P11, midwife).

### 3.2. Support needs and recommendations

Five ‘need’ themes emerged (Table 2). Almost all respondents \((n=24)\) emphasised a need for more support to help mothers adjust or cope. The sub-themes of staff continuity, reassurance concerning the baby, and mental health education for midwives were discussed exclusively by antenatal workers: “When somebody says schizophrenia, especially in midwifery, people get frightened because they think that they’re symptomatic... I think we need more awareness sessions for midwifery.” (P18, registered mental nurse working in the antenatal clinic).

Thirteen participants identified training parents in safety issues and sensitive caregiving as support needs, although they tended not to differentiate the two areas of parenting behaviour (Table 2). Eight participants discussed the importance of maintaining patient mental health, and eight spoke about the need for continuity of care and community support. Whereas antenatal workers discussed the sub-themes, networking within the health service and
parenting groups, two postnatal workers mentioned social and housing needs. The theme, ‘encouragement and opportunity to bond’ also emerged, which included providing one-to-one time to postnatal mothers in a supportive environment, and working with mothers to consider her infant’s needs before her own.

When asked how women’s needs could be met by services, workers discussed four themes (Table 3). Postnatal staff tended to think that needs could be met by developing secondary services and informal community support (e.g., mother and toddler groups) to complement existing services.

Several respondents reported having minimal or no knowledge of the specific community services available locally to mothers and infants. Antenatal staff tended to recommend the development of primary services, particularly the continuity of service support through pregnancy and the postpartum period.

3.3. A proposed parenting program: The BABIES Project

The proposed parenting program was described to workers towards the end of the interview. Twenty-six of 28 participants reported that, in their view, the program

Table 2
The needs of mothers with schizophrenia: health service workers’ views and sample quotes

<table>
<thead>
<tr>
<th>Theme</th>
<th>n</th>
<th>Sub-themes</th>
<th>Sample quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of primary services</td>
<td>21</td>
<td>Health visitor* and community psychiatric nurse involvement</td>
<td>“If a community midwife finds a woman with schizophrenia, I think they need to liaise with a multidisciplinary liaison to make sure that all her needs are being catered for.” (P19, registered mental nurse)</td>
</tr>
<tr>
<td>Development of secondary services</td>
<td>17</td>
<td>Specialist inpatient units and specialised services</td>
<td>“We’ve got started group work as well once. We try to do that once a week for mums and... If that was carried on in the community, they’d have to make sure this consistency which could help.” (P6 registered mental nurse)</td>
</tr>
<tr>
<td>Community services, parent groups, and education</td>
<td>11</td>
<td>Informal community support</td>
<td>“Mother and toddler groups that are already in the community. Could be more aware.” (P2, registered mental nurse)</td>
</tr>
<tr>
<td>More social services involvement</td>
<td>6</td>
<td>Voluntary agencies and self-help groups</td>
<td>“Social services are already very, very oversubscribed... They’ve done a lot of work for them... Perhaps even start a new service.” (P14, midwife)</td>
</tr>
</tbody>
</table>

* A health visitor in the UK is a qualified nurse/midwife who home visits to provide practical help and advice most often following postpartum care.
would be effective for mothers with schizophrenia. When asked about any concerns they might have, 12 had none to report. The remainder elaborated on their concerns from which eight themes were identified, which could be categorised into patient factors (motivation and wellness: n=7; approach, consent and confidentiality: n=3; expectations and distress: n=5); intervention program concerns (timing and length: n=9; use of video feedback: n=4; personalisation: n=3); and research factors (short-term research context and evidence: n=3).

Concerns about the intervention’s timing and length focused on the program being too brief and starting too long after delivery of the baby, and sessions being too long. The effectiveness of the program was felt to depend on the severity of the patient’s illness and the patients’ need to feel the benefit herself in order to motivate participation. Respondents also felt that women may fear disappointment if they have high expectations of themselves, or that the program could exacerbate women’s anxieties about their ability to parent: “Setting up to fail sometimes and we push bonding...We know the outcome is not going to be good really. We give them a chance...encouraging them, do this for baby, talk to your baby, bond with them, and you just know it’s not going to, or if it starts to happen... But it’s just circumstances. It’s not gonna carry on. And then it’s like tearing them back apart again.” (P5, nursery nurse).

Some respondents questioned whether video-based feedback could be used positively or whether a structured program would allow for a personalised approach: “I know you said you’re going to focus more on the good bits and on the positives...But they might think oh you know, what’s she talking about? Why’s she telling me I’m doing this wrong?” (P9, registered mental nurse).

In a structured part of the interview, we asked workers on a four-point scale how useful and how difficult they felt this group would find particular aspects of an intervention. Not all aspects suggested were part of our proposed intervention. Most respondents considered the following methods to be quite, or very, useful: practical advice about childcare (n=26); video feedback to enhance the quality of mother–infant interaction (n=26); and cognitive training to improve facial emotion processing (n=24). At least half of the sample felt video feedback (n=15) and practical advice (n=20) would be quite or very easy ways to involve mothers. The following aspects were thought to be difficult for mothers with schizophrenia by many respondents: discussions on the mothers’ attachment with own parents (n=22); program sessions of 1.5 h’s duration (n=21); cognitive training to improve facial emotion processing (n=18); keeping a baby diary for 3 days to encourage reflection (n=18).

When asked about other methods for supporting these women, eight respondents expanded on the training of parenting sensitivity. Sixteen respondents had further suggestions, from which seven themes emerged (Table 4). Most emphasised the need for support and resources to help mothers adjust to parenthood in the community, such as

<table>
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<tr>
<th>Theme</th>
<th>n</th>
<th>Sub-themes</th>
<th>Sample quote</th>
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<tbody>
<tr>
<td>Ongoing support from services</td>
<td>8</td>
<td>Phone contact and home visits</td>
<td>“I suppose making sure they’re signposted to relevant agencies that again can give consistent support and advice. So that when one level of support ends, there’s an overlap with a second level of support, so they’re not left high and dry.” (P28, midwife)</td>
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<td></td>
<td></td>
<td>Keep services informed</td>
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<td></td>
<td></td>
<td>Provide information about local services</td>
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<td></td>
<td></td>
<td>Family support, parenting and play groups</td>
<td>“It would be useful to then go onto some kind of playgroups...lots of areas have them...even health centres, or resource centres have access to different kinds of play groups and family support groups.” (P1, registered mental nurse)</td>
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<td></td>
<td></td>
<td>Awareness of local resources</td>
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<td></td>
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<td>Drop-in clinics</td>
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<tr>
<td>Community group contact</td>
<td>6</td>
<td>Earlier researcher contact</td>
<td>“This behavioural intervention should not be seen as an isolated intervention...be integrated with other interventions in the same way...Joined-up working.” (P26, consultant obstetrician)</td>
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<tr>
<td></td>
<td></td>
<td>Liaison with services</td>
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<tr>
<td>Improve education</td>
<td>4</td>
<td>Midwife education</td>
<td>“I think it’s educating us [midwives] and I think it’s publicising it more so that the women are not embarrassed...I don’t know enough about mental health...I think generally people are more sympathetic to people that have got a physical illness or they’re in pain or they don’t look well as opposed to mental illness.” (P24, midwife)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Improve public awareness and understanding</td>
<td></td>
</tr>
<tr>
<td>Family support</td>
<td>3</td>
<td>Family support</td>
<td>“...Involving partners I would imagine would be important.” (P25, senior registrar in psychiatry)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Partner involvement</td>
<td></td>
</tr>
<tr>
<td>Other parenting sensitivity techniques</td>
<td>2</td>
<td>Baby massage</td>
<td>“Practical sessions like baby massage and things like that...I think baby massage is really good...A lot of the mums in their next pregnancy do tend to tell us about baby massage, how much it helps with the bonding process.” (P12, midwife)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encourage breastfeeding</td>
<td></td>
</tr>
<tr>
<td>Funding for future services</td>
<td>1</td>
<td></td>
<td>“Also strategically maybe funding for future things, maybe resources because we [antenatal clinic] are a Cinderella service for mental health.” (P18, registered mental nurse)</td>
</tr>
</tbody>
</table>

Table 4
Alternative recommendations for intervention: health workers’ views and sample quotes
parenting groups, home visits and family involvement. Other suggestions include the need for midwife education and raising public awareness of mental illness, and the need to integrate research into the service.

3.4. Overarching themes

Two themes recurred across topics in the range of participant occupations. Firstly, workers emphasised a lack of, and need for, the integration of services and continuity of support. Antenatal workers tended to know little about postnatal services, and neither group had sufficient knowledge of local community services, or an effective mechanism for partnership working. A second recurring theme was a perceived ignorance and social stigma attached to mental illness in society, which extended to healthcare workers. Some felt that this sometimes led to negative preconceptions among workers concerning the abilities of mothers with serious mental illness to be ‘good’ mothers and to their negative treatment by workers who misunderstand — particularly antenatally — the nature of their symptoms. Some respondents pointed to the need for more education within services, particularly for midwives.

4. Discussion

This is the first study of the needs of mothers with schizophrenia from the perspective of health care providers involved in their perinatal care. From the perspective of the interviewer, a qualitative approach encouraged openness among healthcare workers, many of whom found this a sensitive and difficult topic to discuss. Their views complement other sources of data, such as the service user perspective, to inform service development. The three participating hospital sites offer some existing specialist mental health provision, which is unlikely to be representative of services in the UK or worldwide. Despite this, respondents in this study tended to express a lack of sufficient support and appropriate services for this highly vulnerable group, and a lack of mental health training or knowledge of relevant local services.

The two overarching themes that emerged are consistent with the experiences of mothers with severe mental illness. UK and Australian studies of such patients highlight a lack of service continuity to be problematic, although these studies did not focus on the perinatal period [1,3,23]. In an Australian study of mental health workers, work issues were viewed as a barrier to effective service delivery for parents with mental illness, including other agencies addressing the children’s needs, limited knowledge of child protection services and a lack of understanding of the parent’s mental illness [23]. In the current study, workers recognised that a lack of continuity of care was a major obstacle to supporting this group in their transition to motherhood. Specific recommendations include better communication between services, more intensive health visitor and community nurse involvement, extending current services to community support, links with voluntary organisations, better knowledge of informal support groups and local resources, and family involvement. Perhaps surprisingly, few workers considered family involvement to be a key element of service development, in contrast with previous studies [1,3].

Participants recognised the difficulties mothers with schizophrenia face due to the stigma attached to mental illness, and to schizophrenia in particular, in society and among healthcare workers. Stigma was believed to impact on maternal mental health and stress generally as well as on the quality of antenatal care mothers receive. This view is highly consistent with mothers’ own reports in previous studies, including their treatment by mental health professionals and particularly on their right to be, and adequacy as, parents [2–4,7]. Mental health education for midwives was repeatedly recommended, mainly by midwives. The interviews may have led some workers to realize how little they knew about how to support this vulnerable group. Indeed, another study prompted workers to request training sessions from the researchers based on study findings [4]. Raising public awareness and school education were also suggested.

Nearly all our sample discussed the need to support mothers to cope and adjust to parenthood, and to reduce their anxiety both within their immediate setting and outside. No workers focused on the fear mothers may have of having their child removed to custody, despite its prominence in the discourse of mothers with mental illness [1,3,4,7,9]. Rather than proposing this as a rationale for providing additional support, a few participants discussed how this fear impacted on some mothers’ behaviour towards healthcare workers, which was raised as an obstacle to providing support. Almost half the sample discussed a need for one-to-one work regarding practical parenting skills and improving parenting sensitivity. Service users have not expressed such a need in previous studies. A Canadian study offered a different view by exploring with mothers with severe mental illness the strategies they use to imitate ideal perceptions of mothering, such as ‘masking’ and ‘censoring speech’, while attempting to hide their mental illness from their children [8]. Observational studies suggest that mothers with schizophrenia are vulnerable to poor parenting skills and interaction [10–16]. Throughout the interviews in this study, children were mentioned only in reference to maternal bonding and play, and mostly in the context of adjustment to the parental role and the management of anxiety. A few workers felt that the focus was on child needs to the exclusion of those of the mother, which raised an issue of their conflicting needs and not viewing the children’s needs as part of the mother’s needs.

The BABIES Project parenting program was generally well received, although a number of concerns emerged, which will be investigated further as the intervention is implemented. Perhaps unexpectedly, of all our sugges-
tions, respondents reported the provision of practical advice on childcare to be both the most useful and most simple for this group, but which we may expect to exist already in routine practice. While practical advice on parenting is certainly useful for the safety and health of the child, little evidence shows that the provision of information can enhance the mother–infant relationship [26]. Particular aspects that we had planned for our intervention (i.e., video feedback, baby diary, 1½-h sessions) were considered to be quite, or very, useful for this group by most workers, although a minority felt them to be too challenging. The findings suggest strongly that such an intervention needs to be embedded within existing support and services as a package for mothers before it is acceptable to perinatal health workers. The views of MBU workers may be distorted by their contact with the most vulnerable mothers, as they tended to be more negative about the effectiveness of an intervention in these women.

This study has several limitations. As health workers were approached to participate in the study in the workplace, as arranged through clinic/ward managers, some workers were ‘unobtainable’, particularly senior professionals on the pretext that they were ‘too busy’. Although we have no precise figures, we estimate that at least 75% of workers participated in the study, including the vast majority of MBU workers. The sample consisted mostly of midwives whose task is to focus on specific aspects of patient care. Some workers reported not knowing the specific diagnosis of patients; thus responses reflected their experiences with women with psychotic disorder generally. Interviewer bias must always be considered in qualitative studies; in this context, unmet patient needs may be of more interest than existing services. The services provided by the three sites are unlikely to be representative, but responses highlight the service needs of mothers with serious psychiatric illness even where specialist support is available. Patients may have contrasting views from workers about their support needs; therefore, a fuller picture may be gained by interviewing patients themselves.

5. Conclusions

This study highlights the needs of new mothers with schizophrenia, as viewed by perinatal health service workers, and the obstacles to developing services to support this high-risk group. Multi-level support is suggested by workers where it is not currently met by hospital or community services. The poor awareness of many health workers of the complex needs of new mothers with schizophrenia may contribute to difficulties in developing evidence-based support, especially parent training. There is a need to educate ante/postpartum health service workers in mental health, so that workers understand parenting and child needs within the context of women’s mental health.

Acknowledgments

This study was supported by a research project grant from the Central Manchester and Manchester Children’s University Hospitals NHS Trust.

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