

An evaluation of services provided by Bluebell Care for parents experiencing perinatal mental illness in Bristol over the two year period 2013 – 2014



" I feel 100% different to when I started with Bluebell and I still get a bit choked up when I say that. "
(Hannah, mum supported by Bluebell and now working with us.)

" Perinatal mental illnesses are a range of conditions, which affect at least 10% of new mothers ... it is critically important to identify women who are at risk and ensure they get timely and appropriate support. "

Prevention in Mind, NSPCC, 2013

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1. Project Summary

This report covers the two-year period of 2013 and 2014, during which time Bluebell has been providing community services for parents experiencing pre and postnatal depression & anxiety (perinatal mental illness) in Bristol, funded by the Big Lottery and others.

The main services provided by Bluebell are:

- Mums' Comfort Zone - a 12-week therapeutic course for mothers experiencing pre and postnatal depression, delivered in Children's Centres, in disadvantaged areas of Bristol.
- Bluebell Buddy Service - a one-to-one listening and befriending service delivered by trained Buddies, who are mothers with lived experience of perinatal mental illness, in the home or in local settings to support others experiencing similar issues.
- Dads' Zone - a befriending service for fathers, either experiencing perinatal mental illness or supporting their partner through it, delivered by a trained peer support worker who is a dad with lived experience.

Main Aims:

Through the provision of these services, Bluebell aims to:

- Equip parents affected by perinatal mental illness with tools, techniques and strategies to help them manage their mental health more confidently in their family lives.
- Promote a recovery model by providing strategies and techniques that can be used alongside other treatments and will help to reduce feelings of anxiety and depression.
- Reduce isolation and stigma experienced by parents affected by perinatal mental illness, through providing accessible group & one to one support and connecting them with others experiencing similar concerns.
- Raise awareness and promote better understanding of perinatal mental health with parents, the public and the wider health community.

Bluebell has been successfully meeting these objectives since it began in 2011. An earlier evaluation report can be found on our website www.bluebellcare.org for 2011 - 2012. This report will focus on the period 2013 - 2014.

2. Monitoring and Evaluation Techniques

Right from the start, Bluebell has been a user led organisation. In 2010 we ran focus groups to gather feedback from those with personal experience, to assess where the gaps in provision lay. Out of this consultation, Bluebell's services began and have been evolving ever since.

In order to gather continual feedback from parents using our services, capture the data we need for evaluations, demonstrate our impact, or adapt our services when necessary, we use several monitoring techniques:

- Screening and assessment tools to establish a baseline for parents' mental well being when they first access our services, which are then repeated on completion, to measure progress and recovery. For this we use the GAD(7) anxiety tool and the EPDS (Edinburgh Postnatal Depression Scale) plus our own client detail questionnaires.
- Weekly session questionnaires completed by all parents, to assess satisfaction levels with the sessions, as well as their weekly mental wellbeing.
- End of programme questionnaires completed by every parent on completion of a programme, such as our 12-week course, to assess their overall satisfaction and journey through the programme.
- Knowledge Cafés - creative evaluation sessions at the end of each programme, where parents can express through drawing, doodling and writing on tablecloths, their reflections on their feelings completing a programme, compared to how they felt when it first began.
- Interviews with our Bluebell Buddies on home visits or in the group settings.

2.1 How we demonstrate our impact

Through using these tools, we have gathered evidence to demonstrate how well we are meeting our objectives and the impact on parents' recovery and mental wellbeing, which we use to reflect on ways we can adapt or improve our services and to share our learning with others. Some of the audiences we share our learning with include: funders, health professionals, commissioners, parents, the wider health community at conferences and the media. After each Mums' Comfort Zone course we also provide an evaluation report for each Children's Centre we work with.

In addition to our planned outcomes, we see many unexpected outcomes from our services. In many ways, Bluebell Place, the project we are planning now, is an unexpected outcome that has arisen from our existing services and is a need that has been identified by parents, over the past four years.

Other unexpected outcomes we have seen:

- Many parents accessing our services have become highly motivated to help others in similar situations and as a result, plan to volunteer at Bluebell Place. We already have previous service users working for us as Bluebell Buddies.
- That on completion of our programmes, parents have started their own mutual support networks and now express a desire to meet somewhere in a shared hub – re-enforcing the need for Bluebell Place.
- That we receive many more referrals than expected via IAPT service providers, and as a result, we are meeting with our local CCG commissioners to discuss how Bluebell's services could become commissioned to meet this need.
- We are approached often by the media, film-makers and academic researchers asking to draw on Bluebell's expertise, services or service-users for research, reports and media awareness. This has been an empowering experience for many of our service users.
- We have started to support more dads than initially expected, often via their partners accessing our services and sharing this with them - another need we plan to meet further through Bluebell Place.
- That Bluebell is asked regularly by professionals and parents from other areas throughout the UK, to replicate services in their areas, leading to recent new developments in Gloucestershire and Devon, which we are currently exploring.

3. The Difference We Have Made - Quantitative and Qualitative Results

Evaluation Methods

An internal quantitative and qualitative evaluation was conducted in accordance with the requirements of the funding organisations. The purpose of the evaluation was to verify whether the charity was achieving its aims of reducing anxiety and depression in mothers through providing them with new tools and strategies for managing their mental health, reducing social isolation and increasing their ability to ask for help. The main question that needed to be answered was whether the anxiety and depression levels of the mothers fell as a result of attending the group programme.

Participants completed the Generalised Anxiety Disorder 7 (GAD 7) questionnaire and the Edinburgh Post Natal Depression Scale (EPDS) before and after the 12 week group programme.

For the programme closure session, participants were invited to join a "knowledge café" where they had the opportunity to visually demonstrate their thoughts and feelings, in relation to the programme, by drawing and writing on paper table cloths.

Data analysis was conducted by an independent research assistant.

As an internal service evaluation, it was decided that formal research ethical approval was not required. Informed consent was sought from all participants and they were aware that their feedback and reflections would be used to evaluate the service. All data protection guidelines were adhered to.

Evaluation Findings

Over 2013 - 2014, a total of 108 mothers were registered to join a 12 week programme at either Henbury Court Children's Centre, St Paul's Nursery School and Children's Centre or Four Acres Children's Centre. Out of 108 registered mothers, 103 joined the programme and 73 finished the programme. Reasons for dropping out included inconvenient timing or venue amongst other unreported reasons. 2 mothers did not fill out their end of programme feedback form with GAD 7 and EPDS scores. The following graphs and reports therefore include 71 evaluations.

Edinburgh Postnatal depression scale

Mothers scoring 10 or greater may have depression. Maximum score = 30.

Generalised Anxiety Disorder 7

GAD7= 0 - 4: minimal anxiety; 5 - 9: mild anxiety; 10 - 14: moderate anxiety; 15 - 21: severe anxiety.

Improvements in Health and Wellbeing

Mothers completed the Generalised Anxiety Disorder 7 (GAD 7) questionnaire and the Edinburgh Post Natal Depression Scale (EPDS) before and after the 12 week group programme. Figures 1 to 3 show the mothers' mean scores on the EPDS and GAD 7 questionnaires from before and after the programme for each centre.

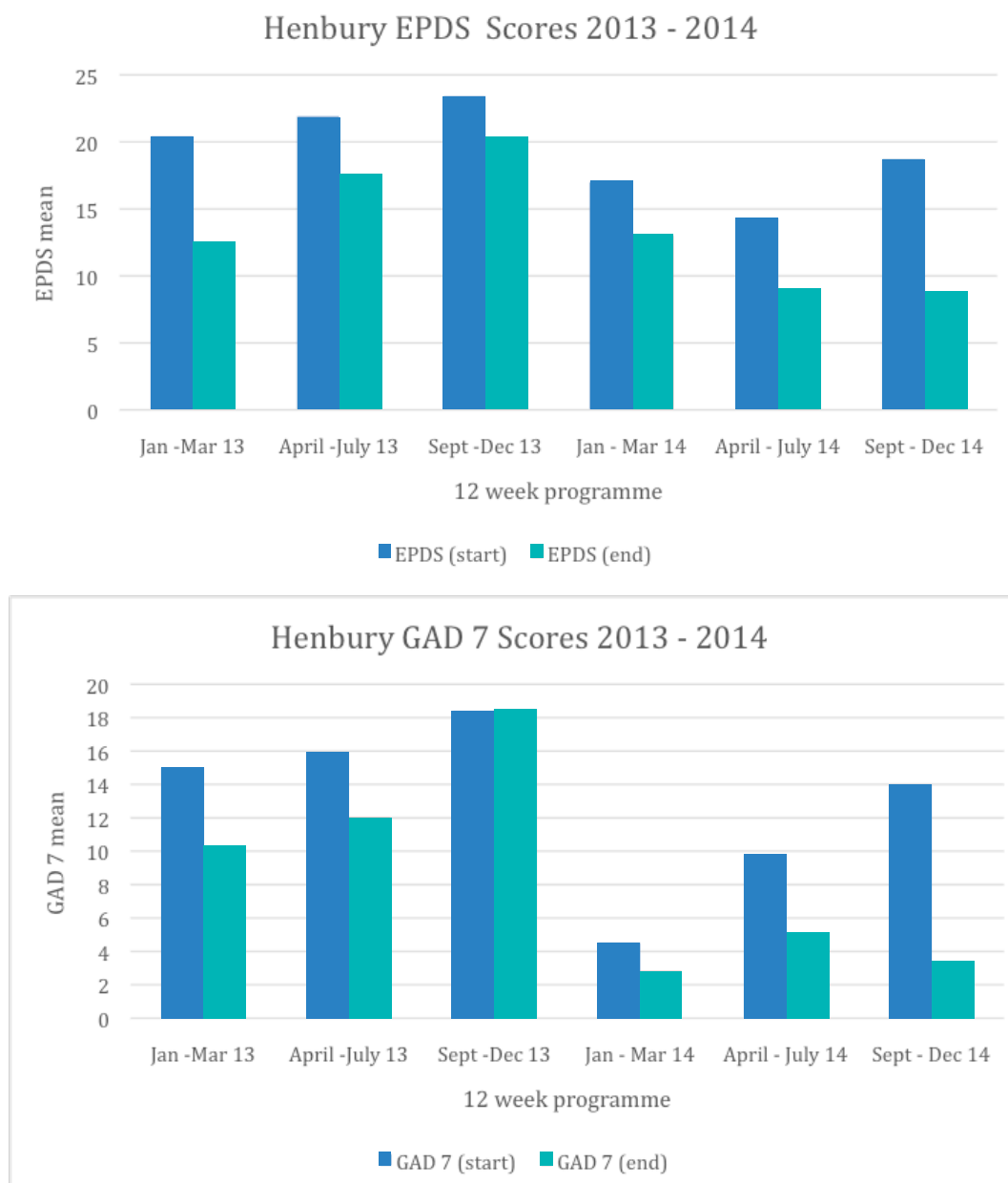


Figure 1: 2 Graphs showing the mean anxiety and depression scores before and after attending the 12 week programme at Henbury Court Children's Centre in 2013 and 2014.

The 12 week programme held from September to December 2013 covered a group of mothers with other psychosocial or medical needs, such as high levels of anxiety, relationship difficulties and comorbidities such as fibromyalgia.

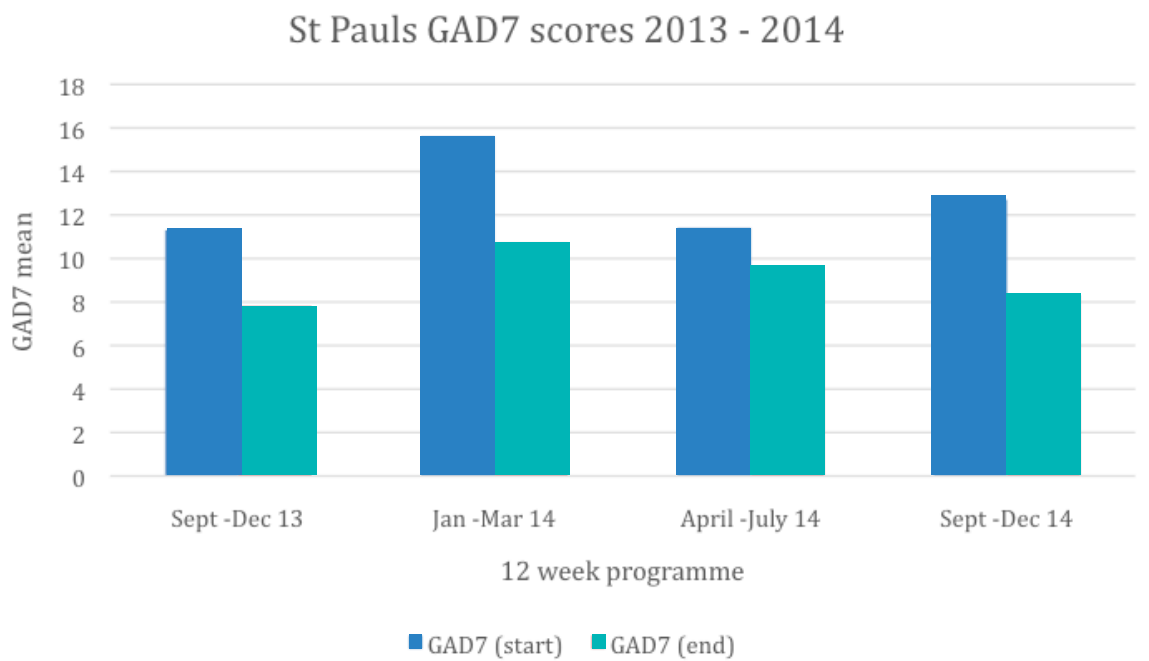
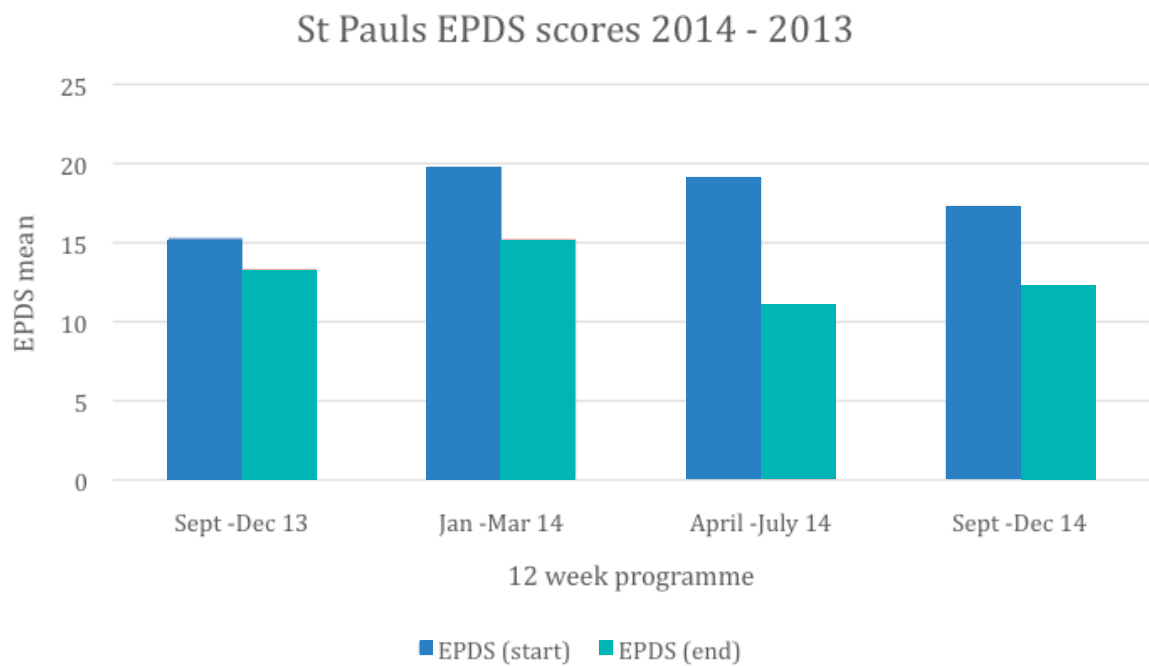
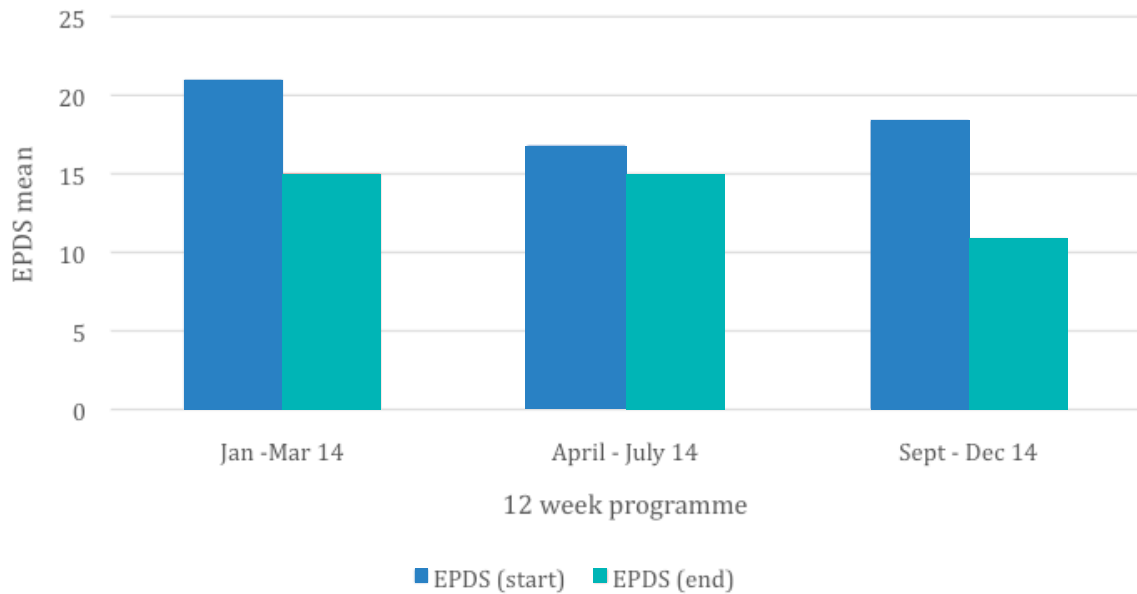


Figure 2: 2 Graphs showing the mean anxiety and depression scores before and after attending the 12 week programme at St Paul’s Nursery School and Children’s Centre.

Four Acres EPDS scores 2014



Four Acres EPDS and GAD7 scores 2014

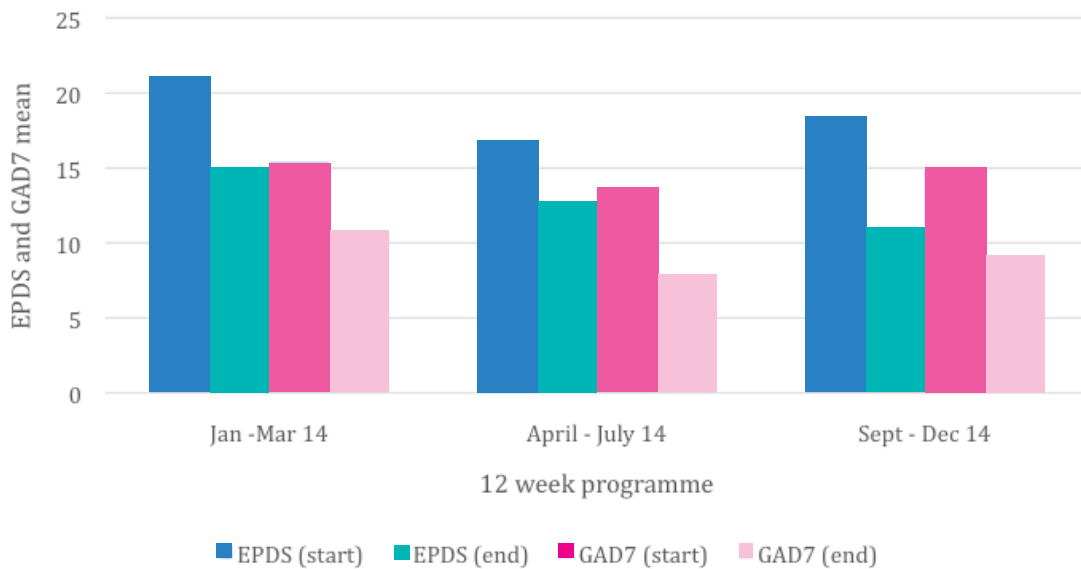


Figure 3: 2 Graphs showing the mean anxiety and depression scores before and after attending the 12 week programme at Four Acres Children’s Centre.

The three centres combined demonstrate a significant reduction in both EPDS (mean of differences = 5.5 (CI= 4.2 - 6.8), $p < 0.0001$) and GAD 7 (mean of differences = 4.4 (CI= 2.8 - 5.9), $p < 0.0001$).

Overall evaluation of the group programme

Bluebell's services were very well received and both mothers and fathers were positive about their involvement with the programme. Clear communication, opportunities to ask questions and be listened to, as well as feeling part of a team, were very highly valued by the attendees.

Participants were asked to rate their overall experience from 1 to 5 (1 = not at all satisfied, 5 = very satisfied) on different aspects of the programme. Whilst no standardised evaluation questionnaire was handed out to every group, "Overall satisfaction" and "How do you feel the overall programme helped you manage your problems better" was rated by every participant. Figure 4 illustrates the overall degree of satisfaction of the programme (%) for the 13 sessions held over 2013 - 2014 in the three centres.

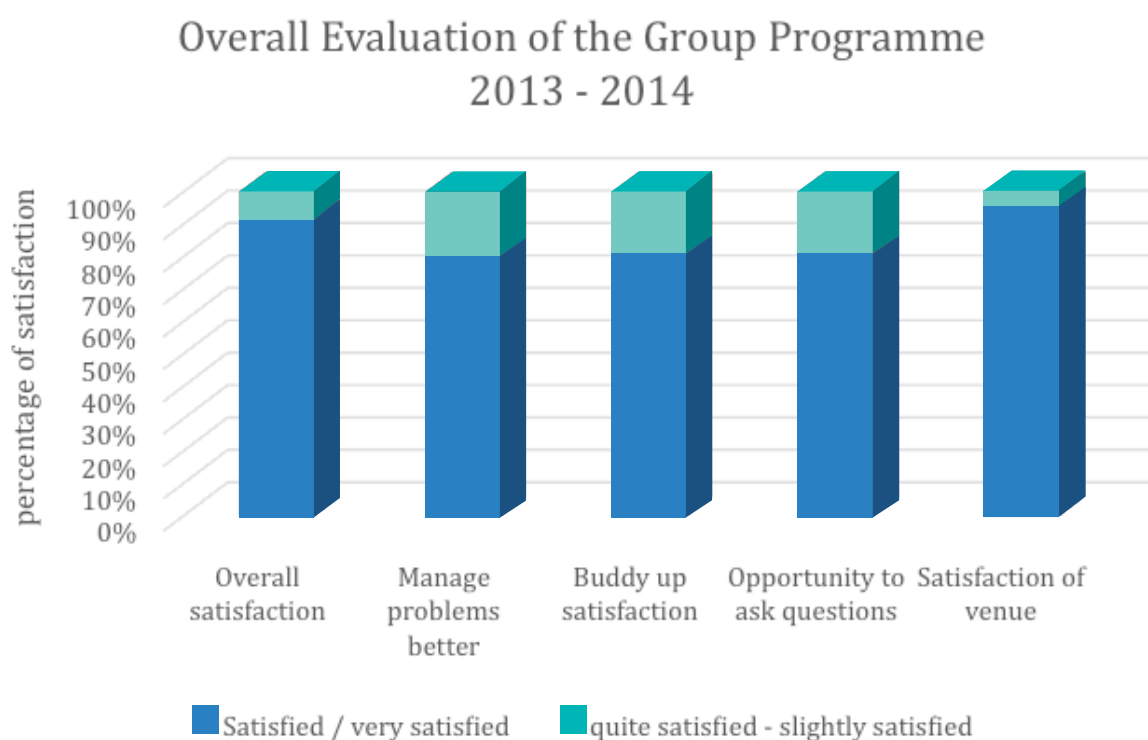


Figure 4. Overall satisfaction of all the 13 programmes held in 2013 -2014 in Henbury, St Pauls and Four Acres children's centre.

Whilst there is an element of heterogeneity in the feedback forms handed out between different groups, most returned feedback ratings showed "satisfied - very satisfied" with a few returning as "slightly satisfied - quite satisfied", leaving room for improvement!

Qualitative Evaluation

In addition to the session and programme evaluation questionnaires, EPDS and GAD 7 tools, a Knowledge Café was run at the final session of the group programme, giving mothers the opportunity to express how they felt at the end of the programme. They were encouraged to be creative through drawing, doodling, sketching and writing on table cloths, facilitating expression, which was especially useful for mothers who may have had some literacy issues or for whom English was not their first language. Verbal feedback demonstrated the benefits of peer interaction, (*"Talking with mums in a similar position helped a lot"; "I'm not on my own"*), as well as building their abilities to process negative emotions, (*"Turning negatives into positives"*) and rationalise their feelings (*"It helped normalise me"; "There is a definition and a name for how I am feeling"*).

Whilst the feedback was positive overall, areas for improvement were highlighted e.g. extending the length of the sessions, improving ease of access and one particularly interesting comment regarding the presence of children at the sessions, which may have reduced the level of engagement from participants.

Positive Quotes

"Talking with mums in a similar position helped alot"

"This helped me to understand why I feel as I do and know I'm not on my own!"

"I have learnt one new thing at every session"

"These sessions help me to make time for myself"

"Turning negatives into positives"

"I've learnt techniques to calm down the blood rush in my body when something bad happens"

"It helped normalise me"

"Gained self-confidence and self-esteem"

"The team has been very supportive all along and especially during the dark days"

"Uplifting"

"Bluebell helped stop the spiralling down"

"Weekly calls were very supportive"

"...there is a definition and a name for how I am feeling"

Dads' Zone Group

The NSPCC (National Society for the Prevention of Cruelty to Children) report on Perinatal Mental Health, published in October 2014, showed that thousands of men experience pre and post-natal depression linked with the pregnancy and birth of their new-born baby. Up to 1 in 20 fathers experience post-natal depression putting huge pressure on the relationship with the partner and the children of the growing family (Bauer et al., 2014).

A new programme, Dads' Zone has been progressively developed by Bluebell since 2012 to support fathers suffering directly or indirectly from anxiety and depressive disorders, related to their partners' experience of pregnancy and birth.

The programme is led by a male peer support worker with the aim of supporting and informing partners of women attending Bluebell's groups. The programme expanded from monthly breakfast meetings to weekly gym sessions together with one-to-one phone support and home visits with the peer support worker. The group started with 6 Dads and those that continued to attend subsequently, became very dedicated, offering each other individual and mutual support.

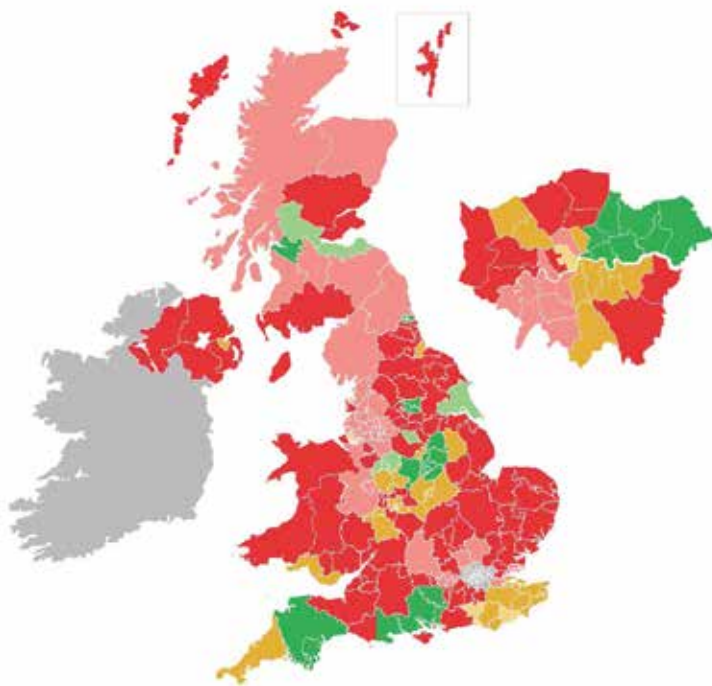
One to one support is greatly appreciated and helps fathers not only by providing an outlet for their psychological strains but also with signposting for social issues such as housing and financial difficulties.

The fathers involved in the Dads' Zone group emphasised their wish to see the programme expand and have a dedicated individual facilitate the one-to-one support, as well as widen the global support accessible in terms of location and times.

4. Gaps in Local and National Service Provision

Over 800,000 live births are registered each year in the UK and up to 20% of women will develop some form of mental illness during their pregnancy or in the first year of the postnatal period. The impact of depression in this group is devastating, with a significant number going on to develop psychosis and some who commit suicide (BJOG 2011). A range of factors has been identified as predictors of developing PND, including previous history of depression, stressful pregnancy and a lack of social support (Robertson et al 2004).

There is currently a national focus on the provision of perinatal mental health services across the UK, with many areas not meeting standards as outlined in the new NICE guidelines for ante and postnatal mental health (2014). The Maternal Mental Health Alliance, of which Bluebell is an active member, recently produced a map, which clearly shows the areas of the UK with a lack of specialist community perinatal mental health provision, with Bristol being a red area; meaning provision doesn't meet national standards. This map can be seen here:



Red areas: no specialist team exists.

Pink areas: some extremely basic level of provision exists but currently falls short of national standards and needs expanding.

Amber areas: some basic level of provision exists but currently falls short of national standards and needs expanding.

Green areas: women and families can access treatment that meets nationally agreed standards.

This highlights the postcode lottery that exists for mothers and families who need support with their perinatal mental health and shows the huge gap that exists for those who don't meet the criteria for in-patient treatment, which is the majority of families Bluebell currently supports.

In addition, Bluebell is a member of two further local teams, both looking at improving perinatal mental health services in the South West of England. These are: the NHS England South West Strategic Clinical Network for PMI (SWSCN) and the Bristol based Health Improvement Team for perinatal mental health (HIT). Bluebell is the lead on both of these for patient and public involvement, ensuring that the service user's voice is heard in the development of these plans. The aim of these groups is to fill the gaps in perinatal services across the South West and to ensure these meet NICE guidelines and national standards for best practice.

Recent reports from the NSPCC (Prevention In Mind, 2013) and The Boots Family Trust (2013) illustrate some of the barriers parents experience when trying to access support, such as stigma and fear.

58% of mums with PND didn't seek help because they feared the consequences of reporting the problem

30% never tell a health professional the true depth of their feelings

41% said their health visitor or midwife never asked about depression

It was significant that 34% of those who admitted they had hidden their feelings said they had done so because they were concerned their baby might be taken away. Also, that social isolation was a big factor for many mothers, both a symptom and adding to their feelings of depression.

“ I avoided friends at all costs as I lost the ability to communicate and became very isolated... ”

“ I was terrified to admit to any health professional as I was scared they would take my son away... ”

***NSPCC Prevention In Mind 2013 & perinatal mental health experiences of parents and professional, Boots family Trust, 2013.*

4.1 How Bluebell fills some of these gaps:

One of the main ways Bluebell fills these gaps is by providing services that enable mothers and fathers to feel safe in sharing their concerns in a way they may not normally do with more traditional services. Bluebell works very closely with health professionals and follows clear safe guarding policies, however, as many of the team are mothers and fathers who have experienced perinatal mental illness themselves, parents often feel more able to discuss their feelings with them honestly. Many parents feel extremely reassured to know that others who have been through perinatal mental illness, are now recovered and able to enjoy happy and fulfilling lives with their babies and families.

Some of the ways our services fill the gaps:

- Providing a Buddy service at home, delivered by trained parents with personal experience, enabling very isolated parents to access support.
- Offering a safe place within our group programmes where mothers feel able to reveal their feelings and fears, knowing they are with others facing similar concerns, who will understand.
- Reassuring parents that with the right support and treatment, they can recover and that being unwell doesn't mean they are a 'bad parent'.

- Encouraging parents to talk to their GP or Health Visitor and helping them to take the first step by accompanying them to appointments if needed.
- Providing a place where dads can access support for perinatal mental illness with other men who have been affected as targeted support for dads is very hard to find elsewhere.

“ I feel 100% different to when I started with Bluebell... after having Noah, I lost who I was. But Bluebell taught me that how I was feeling was normal, it's not something to feel guilty about and there is light at the end of the tunnel ”

*Hannah, Bluebell group member
& now Bluebell Buddy*

5. The Need for Bluebell Place - an ongoing project and further funding

Over the past two years, as Bluebell's services have grown and more parents have accessed its group programmes and Buddy support, parents have repeatedly said they would value a 'hub' where they could continue to access further support or drop-in to meet with others on a regular basis.

Bluebell's group programmes, whilst very successful and a model we plan to continue with, are run as 12-week courses for up to 10 mums at a time. Many of the mothers who complete a course tell us they still feel they would benefit from taking part in workshops and connecting with others, to give them some ongoing support whilst they complete their recovery.

In addition, there are parents who can never fully access Bluebell's services, as either group programmes are full, or Buddies are all busy. Many parents would also prefer to drop-in when needed, rather than sign up to a longer programme. Bluebell Place will provide an accessible place for these parents and break the barriers to accessing support by placing our hub on the high street.

To assess this need further, we consulted with all parents accessing our existing services through questionnaires and ran an online survey through Survey Monkey. We gathered over 200 responses through these methods, which were overwhelmingly positive towards the plans we have for this new project.

These results show:

- 90% of those asked or surveyed were very positive about the project
- 75% said it would help them to feel less isolated & form social networks
- 84% said it would be somewhere they could learn coping strategies
- 90% said they would be very likely to use the service
- 95% said they would use the project very regularly or weekly

Parents' views reflected in these quotes:

“ Somewhere to come for support from others that understand post natal illness; somewhere to talk, have a coffee and cake, to feel less isolated; to do exercise or creative activities : to meet and be with other parents who are struggling ”

“ It would offer a safe space for mums and dads to get support during what can be a hugely difficult and transformative time. This support would help prevent situations from worsening and from more resources to be needed at a later date ”

6. Social Return on Investment - the economic and social costs

The recent report from the London School of Economics, 'costs of Perinatal Mental Health problems', ** highlights both the social and economic costs of perinatal mental illness.

- The average cost to society of one case of perinatal depression is around £74,000, of which £23,000 relates to the mother and £51,000 relates to impacts on the child
- Perinatal mental illnesses cost the NHS around £1.2 billion for each annual cohort of births. In comparison, it would cost only an extra £280 million a year to bring the whole pathway of perinatal mental health care up to the level and standards recommended in national guidance. This is a case for investment that cannot be ignored.
- Specialist perinatal mental health services are needed for women with complex or severe conditions, but less than 15% of localities provide these at the full level recommended in national guidance and more than 40% provide no service at all.

The picture is not good and the full report can be read here:

** <http://everyonesbusiness.org.uk/wp-content/uploads/2014/10/Embargoed-20th-Oct-Summary-of-Economic-Report-costs-of-Perinatal-Mental-Health-problems1.pdf>



In contrast, Bluebell's services not only offer good value for money but also strong social return on investment:

- It costs £2,600 to run one 12-week group programme for up to 10 mothers - £259 per mother. A tiny cost compared to the longer-term costs of not providing support, outlined above of £74,00 and the potential ongoing costs related to child outcomes.
- It costs £225 for one Bluebell Buddy to make 10 home visits to an isolated mother affected by perinatal mental illness - filling the gaps in areas such as Bristol where no other specialist community provision exists.
- In one year, a Bluebell Buddy can visit up to 50 mothers for a cost of £6,750 for each of these mothers to receive 10 home visits - significantly more cost effective than a health visitor, or multiple visits to the GP.

Not only are Bluebell's services saving money for the NHS, but also providing a long-term impact for the whole family and particularly for children. The need for which is shown clearly by the South London Child Development Study, 2011. *

Children of mothers who were anxious or depressed in the perinatal period:

- Had lower IQs at 11 and 16 years of age (20 points lower for boys);
- Were 12 times more likely to have a statement of special needs in primary school;
- Were more likely to have a diagnosis of depression themselves aged 16

7. Plans for Longer Term Sustainability

Since 2011, Bluebell has been successful in raising over £500,000 to develop its services which began in one area of Bristol and now cover North, South, Central and East Bristol. Whilst planning to maintain and build on our income from grants, the charity now has a strategy in place to develop additional unrestricted income streams, to ensure its services are sustainable.

Plans include:

- Selling training in perinatal mental health to the private and public sectors – the team has recently been paid to deliver training for the Norland Nanny College in Bath and has started to deliver workshops for midwifery & health visiting degree students and schools.
- Developing trading income through our new project, Bluebell Place, a high street, centrally located hub, where products, made by mums & dads, can be sold alongside café sales and online sales of Bluebell products.
- Through the commissioning of Bluebell's services through the IAPT re-commissioning process currently in progress in Bristol and due to be put out to tender in early 2016. We are in active discussions with local NHS commissioners about this and intend to bid to become an approved, accredited, provider for the perinatal group programme IAPT service delivery.

In addition, over the past year we have seen our donations from individuals increase significantly with a mixture of Just-Giving income from runners, one off donations and from those with a personal connection to perinatal mental illness. This is an area the Charity Director plans to focus on over the next year and in particular Major Donors, through contacts we have developed in Bristol.

References

NSPCC Prevention in Mind, report 2013, author Sally Hogg

NICE guidelines for Ante and Postnatal Mental Health (2014).

Perinatal Mental Health Experiences of Women & Health Professionals, The Boots Family Trust and Tommy's the Baby Charity (Oct 2013)

Costs of Perinatal Mental Health Problems - London School of Economics
Annette Bauer, Michael Parsonage, Martin Knapp, Valentina Lemmi & Bayo Adelaja - (20 October 2014)

South London Child Development Study, (1986) - used as an ongoing cohort for further studies.

J L Cox, D Murray, G Chapman. A controlled study of the onset, duration and prevalence of postnatal depression. *The British Journal of Psychiatry* (July 1993) 163 (1) 27-31; DOI: 10.1192/bjp.163.1.27

Saving Mothers' Lives. Reviewing maternal deaths to make motherhood safer: 2006-2008; Centre for Maternal and Child Enquiries (CMACE), *BJOG* (March 2011)

E Robertson, S Grace, T Wallington, D Stewart. Antenatal risk factors for postpartum depression: a synthesis of recent literature. (July-August 2004) *Volume 26, Issue 4, Pages 289-295*

Management of perinatal mood disorders; Scottish Intercollegiate Guidelines Network - SIGN (March 2012)