

ICB Public Involvement and Engagement Advisory Committee

Date of meeting	28 February 2024
Title of paper	Developing partnership approaches to public involvement in Blackburn with Darwen
Presented by	Philippa Cross, Associate Director Place Development and Integration, Blackburn with Darwen
Author	Philippa Cross, Associate Director Place Development and Integration, Blackburn with Darwen
Agenda item	7
Confidential	No

Executive summary				
This paper, along with a presentation to be provided at the meeting, offer an overview of recent public involvement activity in Blackburn with Darwen (BwD) and the approaches being developed to strengthen coordination of this work across the breadth of the Place-based Partnership (PBP).				
Advise, Assure or Alert				
This paper is intended to:				
Assure the committee as to the positive approach to public involvement being undertaken across Blackburn with Darwen Place-based Partnership.				
Recommendations				
The committee are recommended to:				
<ul style="list-style-type: none"> Note the update on public involvement across Blackburn with Darwen, including key pieces of regional and system work being developed in relation to co-production. 				
Which Strategic Objective/s does the report contribute to				Tick
1	Improve quality, including safety, clinical outcomes, and patient experience			✓
2	To equalise opportunities and clinical outcomes across the area			-
3	Make working in Lancashire and South Cumbria an attractive and desirable option for existing and potential employees			-
4	Meet financial targets and deliver improved productivity			-
5	Meet national and locally determined performance standards and targets			-
6	To develop and implement ambitious, deliverable strategies			-
Implications				
	Yes	No	N/A	Comments
Associated risks		✓		

Are associated risks detailed on the ICB Risk Register?			✓	
Financial Implications			✓	
Where paper has been discussed				
Meeting	Date		Outcomes	
Blackburn with Darwen Place-based Partnership Board	16/01/2024		<p>The BwD PBP agreed to:</p> <ul style="list-style-type: none"> • Commit to identifying 1 or 2 new programmes of ICB Place / PBP work (e.g. Community Services transformation), where a collaborative approach to co-production could be tested • Establish a mechanism for capturing and monitoring how pieces of insight work are actioned by the PBP • Task the PBP Insight, Communication and Engagement (ICE) Group with co-ordinating approaches across all organisations • Explore whether any resources/capacity could be dedicated to support PBP and adult social care co-production 	
Conflicts of interest associated with this report				
Not applicable				
Impact assessments				
	Yes	No	N/A	Comments
Quality impact assessment completed		✓		
Equality impact assessment completed		✓		
Data privacy impact assessment completed		✓		
Report authorised by:	Neil Greaves Director of Communications and Engagement			

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Developing partnership approaches to public involvement in Blackburn with Darwen

1. Introduction

1.1 The new CQC single assessment framework aims to assess how well care providers, local authorities and integrated care systems are coordinating and delivering care services for local people. Within this, adult social care teams and providers are required to demonstrate how they are involving people in decisions about their care at strategic, operational and individual levels. Similarly Integrated Care Systems are also required to demonstrate how they are considering people's voices when developing and implementing their activity, with explicit reference to the voice of children and young people and other under-represented groups.

1.2 The Blackburn with Darwen PBP have agreed an ambition for their "Delivering with our People" workstream as follows:

"We will work with our residents to improve health outcomes and quality of life, for a happier population".

1.3 Within the PBPs high-level delivery plan, several actions are articulated, these were:

- Embed co-production across the PBP
- Scope out current work and good practice
- Create a culture that enables co-production
- Support specific work ongoing around CYP SEND (Special Educational Needs and Disability) and CYP vaccinations
- Ensure population insight and intelligence drives change – priority wards, dying well, CYP SEND, neighbourhoods
- Empower people to self-care
- Digital inclusion
- Adoption of simple, person-centred communications and language

1.4 In order to help the PBP further shape its ambitions, an engagement and co-production working group was established to look at current work and good practice taking place across the PBP, with a particular focus on the ICB and local authority (due to CQC requirements).

2. Overview

2.1 Since inception in 2023, the PBP, with dedicated support from the ICB's Communications and Engagement Team, have undertaken multiple pieces of

public involvement work which have shaped/are shaping future service delivery in the borough. These include:

- Commissioned priority wards insight work - driving change in the neighbourhood model of care and supporting greater understanding of population need and behaviour;
- Utilisation of community insight (through priority wards and Family Hub parent groups) to develop winter communications and an engagement plan – focused on deep engagement, focus group discussions, messages targeted to insight and community demographics;
- Established relationship with Family Hub parent carer groups – committed to routine engagement and listening, myth busting and raising awareness of key services (engagement report attached as appendix 1);
- Partnering with Healthwatch and parent carer groups to refresh Healthwise booklet;
- Commissioned Dying Well insight work to inform improvements in end-of-life care and the delivery of the Getting to Outstanding Framework in BwD.

Reflections from deep dive on co-production and engagement

2.2 The engagement and co-production working group pulled together several leads from across the local authority, ICB and Together an Active Future (as a key delivery partner) to consider what a partnership approach could look like. Initial discussions identified that a lot of work was already happening in the borough and across LSC, being led by individual organisations. The group sought to understand some of the good practice already being undertaken and began to explore what could be done to help ensure overall effectiveness of these approaches and add value from a PBP perspective.

2.3 Parallel to these discussions, a BwD partnership communications and engagement task group was established, initially with a view to undertaking engagement with members of the public on key winter messages and supporting partnership wide communications throughout the period. This group has representatives from ICB, BwDBC, VCFSE, Healthwatch and ELHT (East Lancashire Hospitals) currently and has recently agreed to take on a more substantive role of coordinating all engagement and involvement on behalf of the PBP going forward. Initial conversations have also commenced as to whether this group could act as a “critical friend” in ensuring the PBP acts on insight generated. Future proposals on this will be brought back to the PBP at the right time.

2.4 Following the review by the working group, several reflections were discussed by the PBP Board, these included:

- Partners in BwD are making their own decisions on, designing and delivering a range of engagement, involvement and co-production – this is a great start,
- Prior to this work it was not obvious that there were strong connections, networks or coordination across partners in BwD and there were elements of duplication/missed opportunities to share insight – the PBP insight, communications and engagement group now have an opportunity to address this,

- There is a diverse and vibrant VCFSE sector in Blackburn with Darwen who are actively engaged with many different residents – this is a key asset within our partnership, but should not be seen as a “free” resource regarding co-production and engagement,
- There are a plethora of organisational policies/strategies/toolkits in existence in relation to engagement, involvement and co-production. However, the production of toolkits and guides does not in itself drive the culture and behaviour change needed to truly put people and communities at the heart of development and delivery – engagement and genuine co-production takes time, staff capacity and resources to reimburse participants for their support
- Many of the examples of co-production found were in relation to the development of strategies or plans and not specifically in relation to the re-design of services – the PBP now has an opportunity to address this.
- True co-production involves going to communities with problems to solve together, not solutions which have already been developed – it takes time to work things through and adequate time to complete strategy/service developments is often not factored in to planning timescales.

2.5 The PBP have subsequently agreed next steps which included:

- Commitment to identifying 1 or 2 new programmes of ICB Place / PBP work (e.g. Community Services transformation), where a collaborative approach to co-production could be tested;
- Establish a mechanism for capturing and monitoring how pieces of insight work are actioned by the PBP;
- Task the PBP Insight, Communication and Engagement Group with co-ordinating approaches across all organisations;
- Explore whether any resources/capacity could be dedicated to support PBP and adult social care co-production.

3. Conclusion

3.1 The BwD PBP aims to embed a focus on public involvement throughout all its service development and delivery, noting that genuine engagement and co-production takes time and resources to complete, so approaches need to be pragmatic and achievable. There are some good examples of co-production already underway within the borough, some of which have been driven through the PBP since its inception, some of which are led by individual organisations. However, the PBP recognises that more could and should be done to increase this and specifically to move this work from being focused on strategy development, into the area of service re-design and transformation.

4. Recommendations

4.1 The committee is requested to:

- Note the update on public involvement across Blackburn with Darwen, including key pieces of regional and system work being developed in relation to co-production.

Philippa Cross

18th February 2024

Family hub parent/carer panels - Engagement insight report

November 2023

Summary

In Blackburn with Darwen there are eight children's centres, four of which have been made into family hubs; these are Darwen, Little Harwood, Livesey and Shadsworth.

The hubs offer support from conception through to age 19, or up to 25 for children with special education needs and disabilities. Parents can also access a range of support through the hubs from midwifery to mental health support, health visiting to infant feeding advice. In addition, the hubs provide early language and communication development for young children to set the foundations for lifelong learning and prepare them for school at age five.

As part of the hub model, parent/carer panels have been developed. The panels allow parents and carers to meet with professionals and help shape and inform services and the delivery of those services to ensure they work for all families in the community.

As the start of an on-going engagement programme with families in Blackburn with Darwen, three engagement sessions were arranged between the leads at the family hubs and Lancashire and South Cumbria Integrated Care Board's (ICB) engagement co-ordinator working within Blackburn with Darwen place. These sessions were held at Darwen, Livesey and Little Harwood family hubs on different days and various times, including the evening, to ensure there was the opportunity for parents and carers to attend. Also supporting the sessions was the ICB's children and young people network and place lead.

The panels were asked what they thought the barriers were to health services, what services they think are missing and how could services be made better for them.

A total of 25 people (excluding children) attended the sessions. Professor Bola Owolabi, Director of Health Inequalities at NHS England, who was meeting with system leaders at the family hub at Little Harwood dropped into the final session for a brief period. She was interested in talking to those parents and carers present and understanding why they had joined the panels and what outcomes they hoped to gain from doing so.

A summary of the themes emerging from all the discussions which took place include:

General -

- People do not know what they do not know
- Health professionals need to take more time in asking more rounded questions and be more proactive in giving information – this needs to be in a more personalised format rather than being given a leaflet
- There needs to be an emphasis on what support is available
- Small inedible portions of hospital food which is of inferior quality and not nutritious – especially for breastfeeding mothers

- Lack of communication between services
- Infrastructure not coping due to the number of new houses being built
- Services being held in different centres/towns, for example blood tests are only carried out at Darwen Health Centre or Barbara Castle Way Health Centre not in GP surgeries so patients must travel between settings – no consideration given to travel costs, time, inconvenience or caring responsibilities
- Patients being passed from pillar to post because services do not always know where to refer
- Disabilities are taboo in the Asian community
- Services within the borough are not equitable – cost of leisure facilities and varying cost of school meals depending on school
- No specific services in place for dads (whether a single parent or a co-parent) – services and language assume a mum is present in the child's life. Dads should be treated as equal care givers with equal responsibility
- Older people appear to be being left behind – no specific services provided such as there are for children and young people such as own emergency department

SEND -

- Carers need support; some have special needs or disabilities too in addition to those they are caring for. There is not enough respite available
- Wrap around services have been lost over the years
- Long waiting times for autism and mental health services
- Parents with a child on the autistic spectrum (whether diagnosed or suspected) need support, information and a point of contact. Early onset support and interventions for parents will produce better outcomes. Equip parents with skill sets i.e. CBT
- Autistic children with mental health issues are falling through gaps for mental health support – CAMHS will not treat the individual as they consider it part of their autism whilst the learning disability service consider them not disabled enough. They need a safe space where they can talk in confidence
- People with autism do not need fixing, they need listening to – suggestion to have autism champions in GP surgeries
- Use social prescribing therapy schemes for those with autism – are these available?
- Use an alert on GP notes so the GP/receptionist is instantly aware of vital details the patient wants to be known about them. For example, details such as: I am autistic; I do not like eye contact; I am trans, and this is the name I would like you to use; my pronouns are e.g. him/her/they

Session 1 - Darwen family hub

The first engagement session was held at Darwen family hub on Tuesday 21 November from 10.30am until 12noon. Although five parents had confirmed attendance, only one lady (with her baby) attended. The discussion centred around maternity and this lady's experience of those services.

Key points:

- Access to dental services is poor – whilst entitled to NHS dental services during and following pregnancy, this lady had to ring around a considerable number of dental practices before finding one who would agree to register her
- First time mums do not know what they do not know:
 - Need to know where to go to register a pregnancy
 - Some morning sickness can be normal but need to know what is normal and what is not and when to seek further advice/treatment (and be aware that anti-sickness medication is available)
 - No information given about the different pathways and potential problems with breastfeeding. Baby struggled to feed, and mum got very sore infected breasts. She joined a breastfeeding group, and it was her friend who told her this was not normal, and that breastfeeding should not hurt. Went to out of hours GP and given medication
 - Health visitor only interested in baby, not mum but mum had problems with breastfeeding (as above). Discovered eventually that baby had tongue-tie
 - Health professionals need to be proactive in personally giving information and explaining the pros and cons of everything. Do not want to be just given a leaflet; would be happy if midwife appointments were longer to be able to discuss any questions and concerns
- This lady had a terrible experience with her first pregnancy (she now has three children); baby was in a back-to-back position (mum already had bad back due to a historical road traffic accident) and when told fully dilated and to push she was only 3cm dilated. She had an infection and baby passing meconium while still inside the uterus
- For her second pregnancy this lady was in full labour for five days. She saw other pregnant ladies go and return with their baby whilst she was told to keep waiting. Eventually she opted for a c-section and even then, the health professionals were reluctant. She was alone for much of her labour as this was during the Covid pandemic meaning her husband could only visit for an hour a day.
- Hospital food is inedible, it lacks nutrition and seasoning. In addition, portion sizes are too small so often left hungry
- Ensure pregnant women are aware that support is available during and after pregnancy

Session 2 - Livesey family hub

The second engagement session was held at Livesey family hub on Wednesday 22 November from 6pm until 7.30pm. Five parents/carers were in attendance including members of Blackburn with Darwen Parents in Partnership (PIP).

Invites to this session had targeted those parents/carers with an interest in special educational needs and disabilities. Discussions centred around mental health, autism and caring responsibilities.

Key points:

- Anyone requiring a blood test across the borough must travel to either Darwen Health Centre or Barbara Castle Way Health Centre; these are not delivered in individual GP practices. This means for example somebody requiring a diabetic/annual health review requiring bloods must have multiple appointments between their own GP practice and phlebotomy services. It can be challenging for those who are elderly, vulnerable, those with caring responsibilities or working people. In addition, not everybody has access to their own transport whilst public transport costs can be expensive
- There are long waiting times for access to specialist services such as neurology and mental health support services
- One parent discussed how her 14-year-old son who has high functioning autism started with epilepsy again in August 2022. He is still waiting to see a neurologist, but mum is unsure if he is even on the waiting list due to lack of contact and poor communication
- Parents/carers need early onset support if their child has been diagnosed with autism or are neurodivergent. There needs to be more information and a point of contact for support. The earlier the intervention, the better the outcome. Parents need to be equipped with the appropriate skills to manage their child's condition; this includes cognitive behavioural therapy skills
- Carers also need support, there is not enough respite available
- Wrap around services appear to have been lost over the years, quality of services is declining
- People who live in Darwen must go into Blackburn for most services. Public transport is expensive and if you have a child with a SEND, you need to do a risk assessment
- Whilst some of the panel members present had difficulty accessing GP appointments, another member was satisfied with her GP practice in Darwen

Session 3 – Little Harwood family hub

The third and final engagement session was held at Little Harwood family hub on Thursday 23 November from 1pm until 2.30pm. There were 19 parents/carers in attendance.

This session coincided with a visit from Professor Bola Owolabi, director of health inequalities at NHS England who was in the area meeting with local system leaders to discuss the challenges faced in the local area. She was invited to chair a section of this engagement session where she was interested to meet the parents and carers and discuss their interest in influencing changes to local services.

Discussions took place around inequity of services.

Key points:

- Services are not equitable within the borough itself: cost of leisure services vary as does the cost of school meals dependent upon school
- Older people are being left behind – they do not have their own services in comparison to children and young people services
- Services are being held in different buildings so having to travel between towns/neighbourhoods for instance between the GP surgery and Barbara Castle Way Health Centre
- There are no services in place for dads – some are having to bring up children on their own in the absence of a mother being present in the child's life. Language and services always reference mum, and this can make single dads feel belittled. Not all mums are present in a child's life. Professionals need training to realise that whatever the status of a dad's presence in a child's life the status of mum and dad should be equally considered
- Children with autism are falling through gaps for mental health support. CAMHS will not treat them as they view their mental health as being associated with their autism, whilst learning disabilities also will not treat them because they do not view them as being disabled enough. They get passed through different services without effective treatment whilst they just need a safe space where they can be allowed to talk in confidence
- People with autism do not need fixing, they just need to be listened to
- GP surgeries should each have an autism champion
- What social prescribing schemes are available for people with autism – one lady found that duck therapy on a farm (privately paid for) worked for her autistic child
- People with a neurodiversity can easily be triggered by incorrect use of language – there should be some short alert on GP notes that flags up vital details that the patient wants the GP to know instantly such as:
 - If they are autistic
 - Their preferred pronouns i.e. him/her/they
 - If they are trans and what their new name is
 - If they do not like eye contact

- Disability is taboo in the Asian community
- Access to foodbanks is through a professional referral – people feel bad enough having to use one without having to prove their need, people could be in a crisis over a weekend with no-one available to refer
- Difficulty in getting to specialised services out of the area – one lady spoke of how her child needs to go to Manchester for an appointment for her child's compressed spine. This lady is on low income, has no private transport, and was turned down for NHS patient transport as not meeting criteria
- Services do not know where to refer so patients get referred either inappropriately or not at all
- Referrals are too multi-faceted, for instance a GP needs to make a referral for an appointment with a paediatrician for a referral to a gender identity clinic

Recommendations

- This insight report is shared with:
 - Blackburn with Darwen place system leaders for them to consider the points raised and feedback any actions
 - Lancashire and South Cumbria ICB Public Involvement and Engagement Advisory Committee for them to consider the points raised and feedback any actions
- Actions and outcomes arising from the insights within this report are shared with the family hub parent/carer panel members
- This continues to be a rolling programme of work and further engagement sessions arranged in 2024

Report Ends