



Research Better Together through participatory research

**Scoping current practice in the
Voluntary, Community, Faith, and
Social Enterprise Sector**

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Executive Summary

Research Better Together is a partnership project between academic researchers, practitioners and support organisations that considers current practice in participatory research within the social care sector in Birmingham.

The partnership has four key partners:

- **The University of Birmingham** who led the project;
- **Birmingham Voluntary Service Council (BVSC)** which undertook research with organisations from the Voluntary, Community, Faith and Social Enterprise Sector (VCFSEs);
- **Communicate2you**, a Birmingham based social enterprise that works with the lived experience of people with a learning disability to improve the communication skills of organisations including health professionals;
- **Co-production Works** who undertook research with the academic community to consider their practice in working with the social care sector.

The partnership is committed to recognising:

- The need to promoting and emphasising the role of service users, communities or people with lived experience in research that affects them.
- The positive role that this research can have in terms of policy development and in the subsequent design and delivery of services, project or initiatives.
- The need to re-balance power and influence towards people and communities.

The research, undertaken by BVSC, aimed to develop a stronger understanding of current participatory research practice in and the needs of VCFSE organisations in Birmingham. It included a series of case studies from VCFSEs to highlight current participatory research activities.

Engagement with VCFSEs working in health and social care proved challenging, not least due to resource pressures. Other challenges in engagement being attributed to the language and terminology used around participatory research, with co-production being a more widely understood approach. There were however some good examples of practice within VCFSEs where their participatory approaches fully incorporated service users within their research practice. These included Communicate2U and Resources for Autism; both organisations working with communities that have experience of learning disabilities. Other examples highlight the work of organisations at the beginning of their journey to adopt participatory research practice and case studies of these organisations are provided at the end of this report.

The project also sought to raise awareness of participatory research and generate interest in future collaboration between health and social care organisations and the higher education research community. Engagement with VCFSEs demonstrated an appetite by the majority of those organisations for further engagement through awareness raising, training and capacity building. Funding was however reported as a significant factor in enabling their involvement. The recommendations of the research undertaken by BVSC highlight the need to prioritise these key issues and to focus on developing a shared vision and understanding of participatory research and the language we use in communicating it.

The recommendations can be summarised as the need to:

- Ensure there is a common and simple understanding of service user/lived experience participation within research, through developing a vision for participatory practice that

promotes the benefits and provides a set of 'drivers' for organisations to improve and implement.

- Undertake further work to raise awareness of participatory practice across the sector, through running further webinars that highlight promising practice and access to resources.
- Build the capacity and experience of VCFSE organisations to either engage with research or to undertake it, through developing accessible training and support and making available information and resources on participatory research on the BVSC website.
- Improve access to funding and/or funding requirements for VCFSEs, through its BVSCs Business Development Network which engages with funders.
- Build up the confidence of VCFSE organisations to engage with academics in the research community, through webinars and a proposed 'matching' activity for VCFSEs and researchers.

1. Overview

1.1. Project Aims & Objectives:

1.1.1. Birmingham Voluntary Service Council (BVSC) is working in a partnership, led by the University of Birmingham, which aims to improve knowledge and understanding of current participatory practice taking place across voluntary, community, faith and social enterprise (VCFSE) organisations. The focus being on those organisations that work within social care in Birmingham.

1.1.2. BVSC has undertaken work to identify examples of participatory research within social care in Birmingham with the specific objectives of:

- Gaining an insight into VCFSE organisation practices in undertaking research
- Finding examples of best practice (case studies)
- Identifying what is working well and what is not for VCSFEs in undertaking research
- Understanding the barriers to engaging with research and barriers to participation
- Identifying what help and support organisations need to enable their engagement / participation in research

1.2. What do we mean by participatory research?

1.2.1. We are defining participatory research as an approach to research that recognizes the need for persons being studied to participate in the design and conduct of any research that affects them.

Examples can include:

- Service users participating in research design or in undertaking aspects of research
- Service user consultations in relation to research
- Co-production of projects and services that incorporate research

1.3. What do we mean by social care?

1.3.1. We are defining social care as support for people to be independent and do the things they enjoy. For example, this can include people who are older, people with disabilities or people who have health conditions.

1.4. Who is BVSC?

1.4.1. Birmingham Voluntary Service Council (BVSC) is the infrastructure organisation for Birmingham's VCFSE Sector.

1.4.2. BVSC supports the sector by providing information, insights, and research on relevant policy and practice and provides effective co-ordination of a range of VCFSE led networks and initiatives.

The structure of the organisation is organised into thematic areas:

- Research
- Grants
- Strategic funding and sector development
- Early help
- Older adults and communities
- Health and Social care

1.5. Consistency of terminology used

1.5.1. We have used the term VCFSEs to refer to organisations from the Voluntary, Community, Faith, and Social Enterprise Sector. We have used the term 'sector' as shorthand when referring to the VCFSE sector in a wider context.

1.5.2. We acknowledge that terminology to describe people who interact with the sector is not uniform and different people have a range of preferences. In this report we have used the term 'service user' or 'people with lived experience.'

2. Undertaking the Project

2.1. Two researchers were allocated to work on the project, Dr Bob Bates and Ian Henshaw. The initial approach was to publish information about the project and put a call out to organisations interested in sharing their experiences. Information about the project was disseminated through BVSC's communications channels which have an extensive reach across its membership, subscribers and networks. Organisations were asked to register their interest on the BVSC website, providing basic information about their organisation and interest.

2.2. The initial call yielded interest from a small number of VCFSEs all of which were contacted and offered the opportunity to be interviewed as part of the research. To increase the number of VCFSEs taking part in the interviews, communications were revised. Researchers contacted BVSC member organisations directly, targeting those who were known to be engaged in co-production and participatory research.

2.3. Through these direct contacts some reasons for the limited engagement became apparent. Several people said that they had seen the communications issued by BVSC but did not think it applied to them as they were not organisations working in social care. One respondent said they were uncertain of whether the research was relevant to them, explaining 'we provide holistic support and care but, I wouldn't consider us a social care organisation.' Other respondents said that they did not understand what was meant by the term 'participatory research,' and they were 'not clear whether the activities they were undertaking met the with the project aims.' This is an interesting finding regarding language and will be considered later in the report.

2.4. Other discussions focussed on whether the participation could be undertaken by service users, people with lived experience (but not service users) and/or citizens. Another issue was whether participation in research activity had to have an academic involvement with one interviewee asking, 'would service user feedback to our mentors (with lived experience) be considered as research?'

2.5. Several respondents offered up views that expressed a lack of interest in participating in the project as they saw no benefit to them, with others feeling that they did not have time to engage with the research as they faced capacity issues. Two organisations expressed frustration at being targeted for 'yet another research project.' Several did not feel they had done any relevant work during or since the Covid pandemic.

2.6. A number of those interviewed explained that they did not necessarily see the need to involve service users in any decision making, design or research activity and, as one interviewee put it, 'doing so is problematic and time consuming' whilst another explained that in their experience their service users just aren't interested in being involved.

2.7. Feedback was shared with the project's steering group, and it was agreed to alter the communications and widen the definitions of participatory research and social care. It was agreed to

supplement the information gathered at interviews with a short survey for organisations to respond, hosted on the BVSC website.

2.8. Researchers further suggested engaging VCFSEs through a standing BVSC business development webinar to look at the issue of participatory research and co-production in commissioning decisions. The Webinar attracted over 40 participants. BVSC also suggested interviewing local commissioners as part of the research to develop a better understanding of the increasing importance service user voices are having within commissioning.

2.9. BVSC communications and marketing attracted interest from a range of organisations, with:

- 38 VCFSEs completing a short questionnaire.
- 34 VCFSEs attending webinar / participating in discussion
- In-depth interviews undertaken with 16 representatives from VCFSEs
- Interviews with 4 commissioners (Health, Local Authority, Criminal Justice, VCS)
- Ad hoc conversations

Organisations that responded were drawn from varied backgrounds including grassroots organisations, micro and small VCFSEs and several larger charities.

3. Findings from Interviews

3.1. A semi structured interview used questions agreed by the project's steering group and as part of the University of Birmingham's ethics approval for the research.

3.2. Interviews were undertaken with organisations, between February and April 2022, and these fell into three distinct categories:

- VCFSEs (16)
- Commissioners (4)
- BVSC programme managers (4)

3.3. Those VCFSEs that volunteered to participate in the research were sent, prior to interview, information about the project and the questions to be used in the semi structured interview. The questions being:

- Can you tell me about your participatory research/education activities?
- Who are you working with on these activities?
- What benefits and challenges does participatory research bring to your work?
- What additional support or resources might you benefit from to better deliver your participatory research/education?
- Are you aware of any other people or organisations in the social care sector also doing participatory research/education?

The organisations that were invited to interview did not identify exclusively as social care organisations.

4. Activities undertaken

4.1. Activities undertaken by VCFSEs

Most of the VCFSEs interviewed for the research provided a general overview of their organisation and described the work they deliver, the people they work with and the communities they serve. Of those interviewed only three were engaged in what they identified as participatory research. These

included Resources for Autism West Midlands who have embedded participatory approaches within their service and now employ a researcher with lived experience and Communicate2U who are a partner of the project.

4.2. Activities undertaken by BVSC

Programme managers from BVSC referred to pockets of good practice and referred to the large programmes previously that BVSC had co-ordinated in recent years, Ageing Better and Birmingham Changing Futures Together. Both programmes had established co-production methodologies embedded within their respective delivery. BVSC has itself committed to promoting service user involvement and has included within its organisational plan aims that:

- Increase the level of co-production and codesign across the city within VCFSE activity and within partner organisations
- Build research and evaluation capacity and understanding across the VCFSE sector in Birmingham

4.3. Activities undertaken by Commissioners

4.3.1. Commissioners indicated that whilst they would like to see increased levels of service user engagement and involvement in the design and delivery of services, they had limited knowledge of examples where participatory research is currently undertaken. One commissioner explained that whilst they place importance on the role of lived experience in the design and development of a project proposal (co-production) that they did not know the extent to which their providers invested in participatory research or indeed whether their work was routinely evaluated outside of any contractual requirements.

4.3.2. Two commissioners believed it was far more common for them to ask questions in commissioning about how service users might have been involved or consulted in the development of a specific proposal. Demonstrating that the potential service provider takes account of service user views. They felt participatory research would be more usual for an evaluation of a project or programme to be commissioned outside of the contract or grant arrangements with the provider, and that this might be dependent on the level of funding.

5. Who organisations are working with

5.1. Who VCFSEs are working with

5.1.1. Eight of the organisations interviewed had limited or no experience of involving service users within their running, management or service design. However, these organisations did express interest in developing approaches to incorporate service user involvement within their service.

5.1.2. Several organisations provided examples where they had worked with researchers, although they explained that this was usually as part of a wider research project. For example, a programme evaluation undertaken by researchers of the West Midlands Violence Reduction Unit and another which was working with an evaluation team from a European Social Fund programme.

5.1.3. One organisation had developed a relationship with a researcher introduced to them by their funder (West Midland Police and Crime Commissioner), a relationship sustained over the funding period. The project fits within the terms of our research having many participatory elements (employing staff with lived experience, co-production, and aspirations to develop roles for service users to work on systems level change) and is delivering services within the wider definition of social

care with touch points to Social Services, Birmingham Children's Trust and Probation Services. However, the organisation's Executive Director did not initially identify with our research, explaining that they did not really understand the term *participatory research* and would not consider themselves to fall within the definition of a social care organisation.

5.2. Who BVSC are working with

5.2.1. BVSC has a dedicated Research Directorate, undertaking sector relevant research and evaluation. The Directorate undertakes a broad range of commissioned research and evaluation, often working in partnership with local universities, notably the University of Birmingham, the Institute for Community Research & Development (ICRD) at the University of Wolverhampton and Birmingham City University. BVSC works closely with Commissioners and is also a member of the West Midlands Social Care Research Partnership.

5.3. Who commissioners are working with

5.3.1. Each representative of Commissioners interviewed explained that service user / lived experience participation is important, but its purpose varies. Involvement is often consultative with only some services being co-produced. Citizen panels and service user groups are commonly used as effective ways of enabling participation that informs decision making.

5.3.2. The Deputy Head of Policy at the OPCC referred to the Commission on Gangs and Violence in Birmingham was one example provided where research informing the programme had been undertaken by community leaders. There was widespread participation by people with lived experience which continued in the co-production of the programme of activity that resulted from the Commission's recommendations.

6. Benefits and challenges

6.1. Benefits and challenges experienced by VCFSEs

6.1.1. Of those organisations investing in participatory research there was an overarching driver of inclusion being aligned with their mission and values. They felt that it was critical to the organisation that service user involvement should be a golden thread running through their work, with research being an integral element.

6.1.2. Several VCFSEs that identified as service user led or having been established by people with lived experience, did not identify with the term 'participatory research'. Instead they saw the involvement of their service users and others with lived experience (their staff) as integral to their day-to-day business. One interviewee reflected that 'the way we do things has simply evolved over time with our people being involved in every aspect of what we do.'

6.1.3. Interviewees routinely identified knowledge, capacity and funding as critical issues. It was clear that there were different views held about what participation in governance, co-production and research mean in practice and what the benefits of it might be.

6.1.4. Whilst capacity and funding are overarching issues for the sector in general, more specific issues were highlighted which included VCFSEs not feeling competent or confident engaging with the research community. One interviewee explained that 'we are interested in evaluating our effectiveness, but I don't know where to start or who to contact.' Several interviewees felt it would be helpful if they could be connected to researchers who might have interests in their specific areas.

6.2. Benefits and challenges experienced by BVSC

6.2.1. The experience of the programme managers in implementing co-production and participatory research has led to the identification of some of the common benefits and challenges.

6.2.2. One of the challenges lies in the representation of lived experience, specifically whereby those taking part in participatory activity (co-production / participatory research) are often self-selecting in their involvement. Sometimes this is down to a limited pool from which to draw, for example, when delivering a smaller project with few service users. In other examples, it can be where a group of experts by experience are recruited at a co-design stage and have continuous involvement with subsequent reference groups for governance, monitoring and evaluation. Whilst this may offer continuity it also presents challenges in ensuring wider views held by other service users / people with lived experience are taken into account.

6.2.3. Another issue that emerged is the availability of funding to support participation particularly in either reimbursing costs or making a payment to those engaged in participatory research. The Director of Research at BVSC, explained how this is not straight forward as making payments can be complicated if someone is in receipt of benefits. They feel strongly that if people with lived experience are undertaking research roles, they should be re-imbursed and recognised by payment for their time at appropriate rates of pay or by other means.

6.3. Benefits and challenges experienced by Commissioners

6.3.1. Commissioners emphasised the importance they placed on hearing and listening to service users and people with lived experience. Their expectation is that VCFSEs delivering services build on their day-to-day interaction with service users and the communities they serve. In this way they develop insights into what works, what doesn't, and can share information and make informed recommendations to commissioners.

6.3.2. For policy development and new services they felt that there was an important role for co-production, but they were less clear of the benefits of on-going research. There was a view that too often there was a need to commission services at pace and that this did not always allow for co-production.

6.3.3. One interviewee commented that they did think there was a tendency when undertaking consultation or co-production to hear from the same service user / lived experience representatives. They felt there is a challenge to ensure diverse voices are heard and listened to.

7. Support and resources required

7.1. There was a general view from those interviewed, including BVSC programme managers and Commissioners, that there is a need for further work to enable organisations to better understand the positive role service user / lived experience participation can play in service design, delivery, governance and research. The issues raised by the VCFSEs interviewed included:

- General awareness raising
- Training and capacity building
- Funding
- Where to find / how to access the research community

7.2. Support and resources required - VCFSEs

7.2.1. Of those interviewed several VCFSEs could see the benefits of participatory research and wanted to do more to improve service user involvement but they lacked the time and resources (staff and financial) to achieve this. Some were concerned that they simply did not have capacity unless funding was available to support them.

7.2.2. For several of the organisations the concept of participatory research was new to them, and they felt that the discussion with researchers had helped raise awareness. They felt they would benefit from attending further training and support to build capacity.

7.2.3. One issue that was raised by several interviewees regarded feedback from research they had previously engaged with. VCFSEs who had engaged with research and evaluation activities felt that they had given their time but saw little or nothing in return. However, one of the VCFSEs interviewed felt they had benefitted from participating in an evaluation programme and were able to reference the findings of the research within funding applications.

7.3. Support and resources required - BVSC

7.3.1. BVSC programme managers felt that funding is a key driver to support the development of participatory activities, particularly for research purposes. Examples where approaches drawing on the knowledge and expertise of service users /people with lived experience was most effective, tended to be where organisations were effectively resourced to enable participation. For example, where a funding programme was prioritising or compelling the provider to adopt co-production or participatory research.

7.3.2. Programme managers also felt that it was important to ensure that any service users / people with lived experience involved in co-production were recognised with a minimum of expenses being re-imbursed and ideally a payment or reward (voucher). There was recognition that this is not always straight forward if someone is in receipt of working age benefits.

7.4. Support and resources required - Commissioners

7.4.1. Similarly, service Commissioners find it challenging to resource capacity in participatory activity despite, one explaining 'we don't have a chance to look at involving people in the whole commissioning cycle yet. We don't give ourselves the time to do that,' with another commissioner noting that annual funding cycles, with late notification of budgets, leads to pressure to commission activity at pace leaving little scope for providers to undertake co-production as part of their response to grant programmes or contracts.

8. Knowledge of other VCSFE organisations undertaking participatory research

8.1 VCFSEs

8.1.1. VCFSEs were generally unaware of work being undertaken outside of their own organisation in the wider sector. Two of the VCFSE which invest in participatory research had a clearer idea of what takes place in their areas of work (supporting people with neuro-diverse conditions / early years)

8.2. BVSC

8.2.1. Programme managers felt that in general, co-production is more widely recognised across the sector than participatory research. However, several examples were cited of organisations

undertaking participatory research. Examples included St Basils, Mind and Resources for Autism West Midlands, the latter having participated in the research interviews.

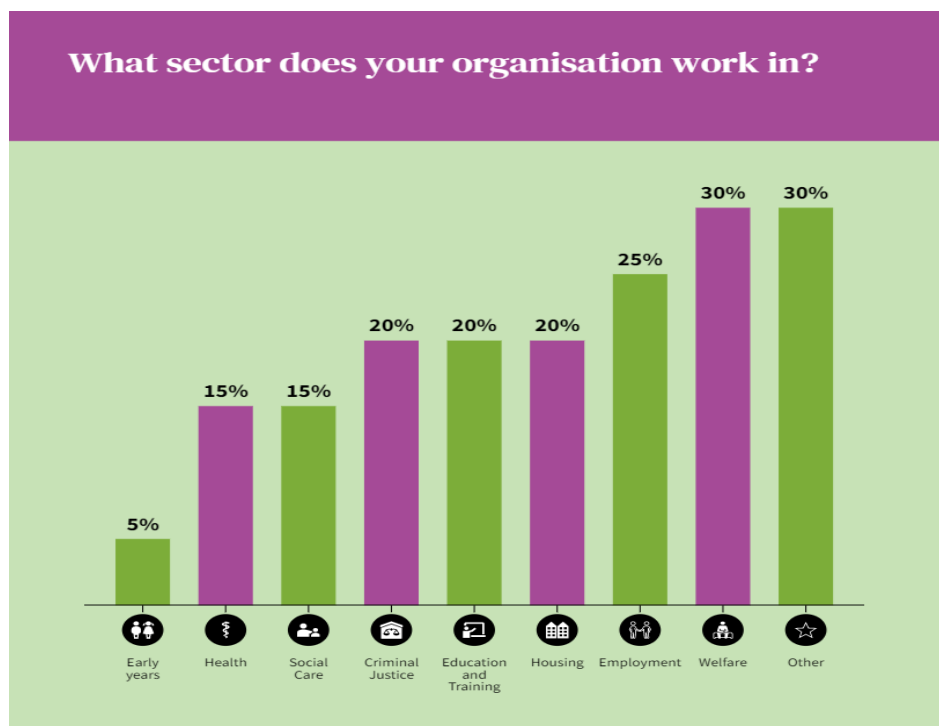
8.2.2. BVSC Research Directorate is leading work on developing sectoral approaches to participatory research, working in partnership with a number of local and national Universities including the University of Birmingham.

8.3. Commissioners

8.3.1. There was limited awareness of any current participatory research being undertaken by VCFSEs, but there were examples of co-production including citizen panels being used within the development of the Integrated Care System.

9. Survey on service user involvement in research

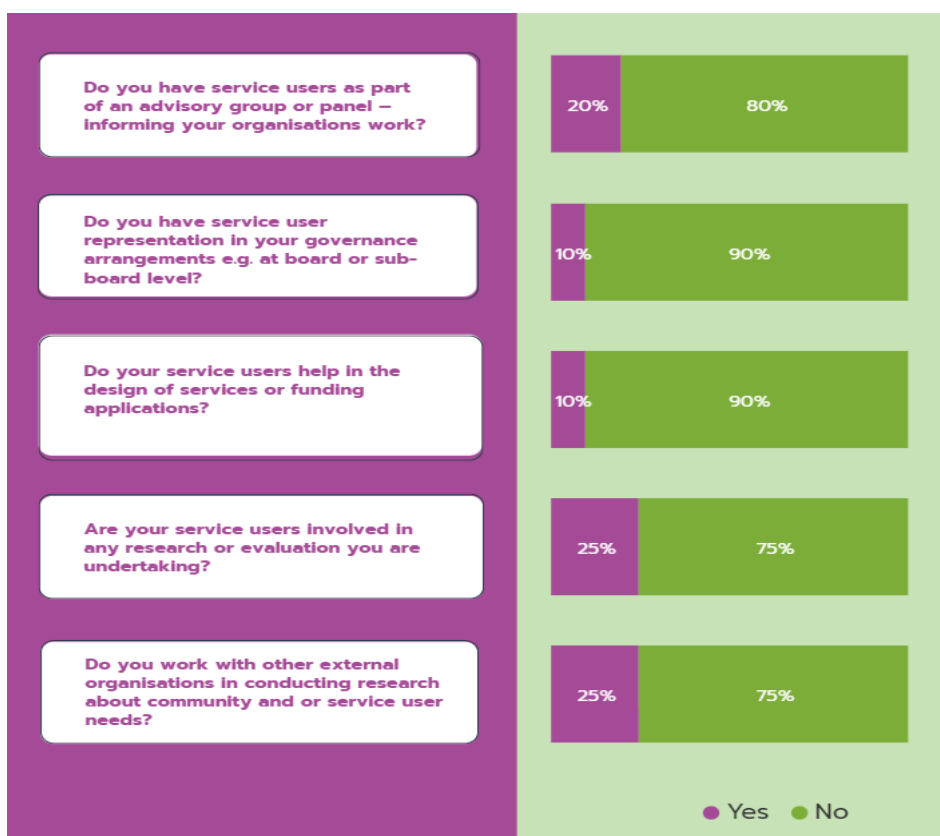
9.1. The following survey was undertaken to further engage with the sector and generate interest in participating in the research. Results from 38 respondents are provided within the tables.



9.2. Whilst the marketing and communications around this project predominantly targeted organisations working in the social care sector, the majority of respondents indicated that their organisation worked within other sectors.

9.3. Those responding also predominantly worked with adults (90%) with 40% stating they worked with communities and 15% with children.

9.4. When asked about operational practices within their organisations, they indicated as follows:



9.4. In general, the survey findings aligned with interviewee responses and ad hoc discussions with VCFSEs in relation to service user involvement in research. It helps demonstrate that there is significant work required to improve rates of service user involvement within governance and influencing VCFSEs development and funding approaches.

10. Summary and Next Steps

10.1. The project has helped identify areas that could be improved to support an increase in the numbers of organisations involving service users / people with lived experience within their governance, service design, delivery, the evaluation of services and research.

10.2. The five areas identified are:

- Shared vision, understanding, and language
- Raising awareness
- Building capacity and training
- Funding
- Help in matching VCFSE organisations with researchers

10.1. Shared vision, understanding and language

10.1.1. The importance of having a common and simple understanding of service user / lived experience participation within research became clear from the interviews and ad hoc conversations the researchers had. Most interviews required the researchers to provide an explanation of the terminology being used. Programme managers from BVSC could be described as having the most

consistent shared view and understanding of service user / lived experience participation, but this should be expected given the role they play in supporting capacity building across the sector.

Proposed action: Developing a vision for participatory practice that promotes the benefits and provides a set of 'drivers' for organisations to improve and implement would be beneficial. One prominent driver being in relation to work undertaken with commissioners and developing and submitting funding applications.

10.2. Raising awareness

10.2.1. As the project progressed the level of interest in it has increased. Interest registered in the webinar series that is being run as part of the programme has exceeded expectation with over 60 people registering to attend.

10.2.2. Feedback from those interviewed suggested that the project had been helpful in raising awareness and interest in service user / lived experience participation and research. The numbers registering interest improved, yet still represents a small number of VCFSEs working in Birmingham.

Proposed action: Undertake further work to raise awareness of participatory practice across the sector. Running further webinars that highlight promising practice and access to resources.

10.3. Building Capacity and Training

10.3.1. Many organisations lack the capacity and experience to either engage with research or to undertake it. This extends, for many organisations, to the scope to embed participatory practice within their organisation, for example within governance or in the development of services.

10.3.2. Access to information and training were referenced by interviewees as important elements for them to engage and develop participatory practice.

Proposed action: Develop a training and support offer that is accessible and make available information and resources on participatory research on the BVSC website.

10.4. Funding

10.4.1. The issue of funding was routinely raised in the interviews. Access to funding and or funding requirements (in grant agreements or contracts) were the most raised issue followed by payments or other recognition for work undertaken by services users / people with lived experience.

Proposed action: BVSC to routinely promote the role of service user / lived experience participation through its Business Development Network which engages with funders. BVSC to help identify funding to build capacity in the sector.

10.5. Help match researchers with VCFSE organisations

10.5.1. Another common issue for VCFSEs was that they didn't know how to identify or feel confident in engaging with academics in the research community. Webinars scheduled as part of the project will help address this as will a proposed 'matching' activity for VCFSEs and researchers.

Proposed action: Undertake further work to build relationships between the research community and the sector and develop process for matching interests.

11. Case Studies

Below we provide a series of case studies to share some of the participatory research activities within VCSFEs. The case studies below are split into two distinct groups. Case studies 11.1 to 11.4 involve organisations that are actively engaging in participative research. Case studies 11.5 to 11.7 are of organisations that are currently exploring different ways to engage with their communities and service users in research and co-production activities. They particularly highlight some of the reported benefits as well as challenges for different VCSFEs when engaging in and undertaking participatory research.

11.1 Case Study: Resources for Autism

Co-production cultural roots

Resources for Autism is a national charity first founded to develop practical services in response to expressed needs and preferences of autistic children and their families based on the principles of compassion, inclusion and collaboration. The charity's historical culture is firmly rooted in the value of accessibility creating positive experiences and spaces where autistic children could feel safe, content, included, accepted and celebrated for who they are.

The growth of the charity's work is founded on its commitment to communication; developing the skills and tools to engage, involve, listen, positively respond to and work in partnership with people with lived experience of autism.

Resources for Autism 2008 expansion to Birmingham was in response to requests by parents and carers seeking local positive and inclusive practical children's services. The charity has continued to develop both in London and across the West Midlands currently providing a range of services for children, young people, adults, and families within the autism community.

Resources for Autism welcomes those with all levels of need.

Children's services include term-time clubs, individual one-one-support, school holiday play schemes, a Play Therapy service as well as groups for siblings. Resources for Autism young people and adult services focus is on wellbeing, positive experiences, confidence, independence and connections with others. These include adult groups, befriending volunteer service, out-reach support, self-advocacy and advocacy and crisis support service. Working with families is core to the ethos of Resources for Autism. Services include peer-led support groups, specialist crisis support and co-produced parent and carer interactive workshops covering emotional regulation, sensory processing, communication, behavioural distress and physical and mental wellbeing.

Transformative Co-Production in Practice

On its co-production journey Resources for Autism continues to build on the positive relationships between staff and people who draw on care and support. Exploring and finding new ways to engage, include and facilitate involvement and participation.

In 2021 a pilot project convened two groups of autistic adults from London and Birmingham in an on-line space with managers to share thoughts and ideas on key resources and services. This included co-designing new website materials to improve accessibility. Other projects include sharing thoughts and ideas to develop autistic adult dating and relationship, walking and virtual groups.

More recently there has been increasing investment in co-production with greater focus on diversity and equality with a specific designated lead, and emphasis on an asset-based approach, understanding neurodiversity perspectives and autism self-advocacy.

Stepping up the Co-Production ladder, Resources for Autism recognises the need for greater movement from involvement and participation towards more equal partnerships. Working together to facilitate more meaningful roles, more powerful influence, more recognition of people's expertise, skills, insights, perspectives and experiences. Reciprocity is a key concept of co-production and is defined as ensuring that people receive something back for putting something in.

Resources for Autism new Co-production Policy sets out how co-production at a personal, organisational and strategic level is reciprocated. This includes (as funds permit) financial payments for people coming together ensuring early involvement in future co-production project and genuine partnerships to identify and shape the changes.

Other developments to embed co-production include co-designing new training materials, 'capturing' evidence of co-production in action to share across the organisation and a new system to collate resources into a co-production 'tool kit'. New training and discussion materials include an 'Introduction to Co-Production' with examples of inclusive co-production in practice. To Resources for Autism Co-production includes everyone, and this means it is not always about coming together in 'formal' meetings. Done well, co-production to Resources for Autism means people who are non-speaking or use other less conventional means to express themselves are all equally part of the same journey.

As part of its co-production strategy Resources for Autism also actively engages in Co-production networking including Birmingham SEND Co-Production group and launched a new co-designed structure that includes a new Co-Production Virtual Forum and 'Drop-In' space for autistic adults waiting to join RfA services. The Virtual Forum is a safe space for autistic adults to come together to share thoughts and ideas, co-design and co-deliver future opportunities to 'connect' virtually. The Drop-In offers a space for autistic adults waiting for services to come together to share ideas and thoughts on what future services should look like.

Resources for Autism acknowledges that people with 'lived experience' are best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production means people using services play an equal role in sharing ideas and thoughts, designing, planning, decision making, delivery and evaluation of experiences and services.

11.2 Case Study: Communicate2U

Communicate 2U is a social enterprise based in Birmingham. It was set up in response to the problem of people with learning disabilities being isolated from society and unable to get the support they need due to the poor communication they encountered with health and social care workers. Their mission is to improve communication in health and social care through training, research, and innovation, whilst working collaboratively alongside people with learning disabilities and those who have alternative communication needs. The company's origins lie in the experience and research interests of their director.

One of the issues that they identified and have sought to address, was the very limited aspirations staff had for the service users they were supposed to support. Research into this issue became the starting point on the journey to establishing Communicate2U.

One of the key issues that initial research identified was that those managing health and social care services did so remotely and rarely saw service users in-person. This disconnect from the people the services were supporting permeated organisational culture and working environments. Members of Communicate2U used creative methods to develop a performance aimed at managers in health and care services in order to challenge their approaches. During the performance they posed questions such as 'Do you know what I like?' and 'Do you know what I want?' to help get managers get to know them better and encourage them to think about good practice in service delivery.

Communicate2U also supported its members to participate in staff recruitment interviews for a service which provided care to people with behaviour that was viewed as challenging.

The organisation drew on research into the positive use of drama for communication by young people with learning disabilities and highlighted the number of excessive deaths of people with learning difficulties attributed to poor communication and staff understanding. They felt that young people with learning disabilities have valuable skills and talents yet struggle to find suitable employment, whilst on the other hand health and social care staff lack appropriate communication skills to work with their service users with learning disabilities. Communicate2U looked to bridge the gap between the two by creating a company where young people could teach people, including health and social care workers, to communicate better.

The Communicate2U model includes a pathway from school whereby the young people do a supported internship. This element of work is not paid, but it ensures that the young communication experts are gaining support and a qualification whilst they understand their role. They then may apply to join a paid work stream having completed their course.

The journey has been one of evolution where today young people with learning disabilities are employed by Communicate2U, albeit on a sessional basis, and their work in training others in communication is highly regarded for its effectiveness. It is important to the organisation that young people receive remuneration that truly values their contribution. Thought and support is given to ensuring any payments made to service-users are in line with permitted and therapeutic earnings allowed by the Department of Work and Pensions so that there is no conflict between entitlement to benefits and the work that happens.

A real challenge for Communicate2U has been to establish a sustainable income model, one not solely reliant on grants. Access to funding has been an issue to their development as an organisation so generating earned income from their training has become an important feature to sustainability.

11.3 Case study: Parental Education Growth Support (PEGS)

PEGS is a nationwide social care charity that supports parents who are abused by their children and who struggle to come forward to seek help and support as they often do not know where to turn or what is available to them. PEGS believe that this increases their risk and isolation from communities and services which is vital to those experiencing this form of domestic abuse. PEGS provide a virtual drop-in session and access to peer support so that parents feel empowered, supported and, consequently, community cohesion is increased. PEGS believe that this will have a positive impact on their emotional wellbeing and increased knowledge of services.

According to PEGS, Child to Parent Abuse (CPA) occurs in at least 3% of households, although they feel that the true figure is likely to be higher given the way that it has historically been underreported and not routinely recorded as CPA. It is described as abusive/violent behaviour towards parents/carers/guardians which goes beyond the normal boundary-pushing displayed by children, over a prolonged period of time. This behaviour can be physical, emotional, financial, or sexual.

According to their research, PEGS estimate that 24% of parents report their child was aged 5 or under when the abuse began, and at the other end of the scale 8% of the families they work with have adult offspring. They also believe that domestic abuse in marginalised communities is prevalent, the vulnerability of migrant and refugee women who may, because of language issues or lack of social contact, be unable to effectively discuss their experiences or ask for help. PEGS want to champion these individuals to become more empowered to speak out, to share their journeys with others in the community to help provide peer support in more localised areas for them. They also give them an opportunity to feel supported, heard and encouraged by their community and to feel safe and included in their lives regardless of their experiences. PEGS's main aim is to help them develop a further sense of belonging and to give them an opportunity to share their voices in a safe way. PEGS believe that giving the voiceless a voice is incredibly powerful, and that this can be achieved by working with them to understand their barriers and to decrease the exclusion they may be feeling in their community.

To progress this idea, PEGS feel that they need to conduct more in-depth research into the problems being faced by marginalised communities, notably focussing on the needs of migrant asylum seeking and refugee women. They are currently undertaking a piece of research in the form of a survey with the 600 parents that make up the group. The survey was designed and conducted in-house, but they have two academics on their board who advise (informally) on its design and delivery. The survey asks key questions about the delivery of the PEG's service and what programmes should be on offer. An example of how the responses to the survey has influenced service delivery is the development of a nine-week programme that focuses on using mindfulness and meditation as a means of addressing the emotional stress caused by children abusing their parents.

11.4 Case Study: At-Pace CIC

At-Pace are a Community Interest Company (CIC) based in Birmingham. Their aims and objectives are about providing community-based learning to bridge skills gaps that prevent young people from communities facing racial inequality who are not engaging in education, employment or training (NEETS) to gain access to mainstream provisions to progress. Their focus is on young people and disenfranchised communities, especially women from communities facing racial inequality who have little skills and/or have little or no confidence and provide them with a ladder of support and opportunity through the delivery of non-accredited and accredited short courses to open new pathways for their progression.

They have a track record of working with agencies such as Birmingham City Council (BCC) directorate teams, the West Midlands Police and Crime Commissioner (PCC), grassroots charitable and voluntary organisations, schools and further education institutions, Department of Works and Pensions (DWP), local businesses and government-funded partners.

At-Pace are currently involved in a project that will train young community journalists (YCs) to gather narratives from residents who will share their stories of what it is like living in Birmingham. They believe in the importance of bringing people from diverse backgrounds and communities together to share their histories through a digital narrative of their neighbourhood as it provides an opportunity to understand one another, celebrate who they are and to be proud of this. They believe that this will aid mitigating cultural, language and confidence barriers. They feel the need to be able to support this idea with robust research to enable them to evaluate the project and to support applications for future funding. The project has been designed in collaboration with BVSC and although this has not involved any of the YCs in the design and delivery of the project, At-Pace are interested in finding out more about how participatory research can work on the project.

11.5 Case Study: Khawateen Creative Minds (KCM)

KCM is a community group, focussing on social care, which has engaged with multiple women from different backgrounds including people from Pakistan, Bengal, Somalia. Their mission is to give their service users and their families opportunities for socialising and working in the community. With a particular focus on women who were struggling to integrate and engage with the wider community. KCM have worked with over 100 families in the past two years.

They would like to continue working with migrant, asylum-seeking and refugee women to allow them to express themselves through art, crafts and gardening. Whilst little research has been undertaken by KCM, they are aware that they need robust research to justify the social value of their work.

Any decisions on the services offered by KCM are made by a committee of three members of the organisation and although they stress that they contact their service users to discuss any changes to existing or developments of new programmes, this is not a formalised exercise and relies on ad-hoc communication.

KCM is still a relatively new organisation and the organisation's chairperson is keen to develop their understanding of different research methodologies (including participatory research) and interested in attending training events.

11.6 Case study: Building Communities CIC

Building Communities is a Community Interest Company (CIC) with a track record spanning three decades; working with, but not limited to: community leaders/members, faith groups, council directorates, West Midlands Police, charitable organisations, volunteer groups and education institutions.

Their mission is to improve the lives of local people, particularly unskilled women. They do this through workshops which focus on enhancing skills, social inclusion and the widening of participation in and pathways to training or employment. They place the emphasis on those individuals who do not meet eligibility criteria for mainstream government funded programmes due to no or little literacy/IT skills and provides them with an opportunity to engage/re-engage in a friendly atmosphere with community-based workshops that they believe will develop participant's basic language skills at a suitable pace, through creative activities.

Building Communities' workshops have initial open listening session so that women can share their challenges, experiences, ideas, knowledge, belief in embracing new improvement approaches to tackle disconnection, heightened anxieties and integration as a diverse community. Through this, they believe that they will provide a sense of acceptance, raise cultural understanding and facilitate social integration. They are mindful that not everyone understands certain languages, so have local bi/multi-lingual volunteers at hand to translate into English and support with written/verbal communication for those who require it.

There is currently no formal involvement by their service-users in advisory groups or in the governance of the organisation; however, they are interested to involve their service users in the design and undertaking of a research project.

11.7 Case study: Birmingham Ethnic Education & Advisory Service (BEEAS)

BEEAS was established in 1984 as a charity to support disadvantaged communities across Birmingham. Their activities support people, particularly women who are struggling to integrate and be fully engaged in their local communities and in the workplace.

Their mission is to work to improve the life chances of people by offering formal qualifications in English as a second language, functional skills, English and maths and digital skills. They also offer informal/conversational English learning, family learning, mental health and wellbeing workshops and signpost people to other organisations for benefit, housing and immigration advice.

BEEAS are currently working with 229 participants; 209 are women from various backgrounds which include Bangladeshi, Pakistani, Somalian, Syrian, Chinese and Eritrean. They also work with Syrian and Afghan refugees to deliver integration programmes. Their research has shown them that many women are isolated from society due to external barriers such as cultural norms, family commitments and general language barriers. They target these women specifically and encourage them through open days, coffee mornings and outreach work.

BEEAS's main aim is to reach out to women and have them come into a setting where they are comfortable, in order to experience social interaction with other women from different backgrounds. For those women who are not able to attend on site due to disability, location, childcare costs and other care responsibilities BEEAS offer online engagement.

They establish the needs of their service users through secondary research taken from existing data. They also use focus groups and student representation on their governing body to gain feedback on their service. Any research is undertaken internally and have never involved a third-party research organisation in this process. BEEAS are interested in finding out about participatory research and are willing to attend future training sessions that will help them build capacity and expertise.