



Our Voice Matters

Phase 1 Findings

October 2019-April 2020

Contributors, Barriers, Solutions

Contents

Sharing Power.....	2
Introduction.....	3
Co-production is a journey.....	4
What is Co-production.....	5
Co-production in Cwm Taf Morgannwg.....	6
Communication: It Flows 2 Ways/It Never Ends.....	7
The Art of Communication.....	8
Conversation Flow.....	9
Conversation Contributors.....	10
What's Stopping Us: the perceived barriers to engagement and co-production.....	12
The perceived barriers for Children and Young People.....	13
The perceived barriers for Older People.....	13
The perceived barriers for people with Learning Disabilities.....	13
The perceived barriers for people accessing Mental Health Services.....	14
The perceived barriers for Parents and Carers.....	14
The perceived barriers for Professionals, Services, Organisations and Projects.....	14
Breaking Down the Wall.....	15
Solutions Hub.....	16
Conclusion: Keeping people with lived experiences at the heart of everything We do.....	18
End of Phase 1 Recommendations.....	19



People with lived experiences, professionals and services
SHARING POWER to get the job done right!

Introduction

Co-production is an essential ingredient identified within the Social Services and Wellbeing Act (Wales), 2014 regarding how social care services and providers across Wales should operate.

This outlines that decision makers need to involve and recognise that people with lived experiences have a vital role to play within the creation and ongoing shaping of the services that exist to help and protect individuals categorised within the Act as vulnerable. As a result, co-production was featured as a key priority within the Cwm Taf Morgannwg Regional Plan and Transformation Plan but with little focus on how this would be achieved. In 2019, a small consortium of third sector organisations (InterLink, RCT People First and The Grapevine) came together to develop a response to this push towards co-production from a citizen led viewpoint that promoted the elements of Voice, Choice and Control, as a mechanism for people with lived experiences to feed into both local and regional decision making processes effectively; resulting in the formation of the Our Voice Matters project.

With the securing of Integrated Care Fund funding, the Our Voice Matters project officially launched in October 2019 following the appointment of a Regional Engagement and Co-production Coordinator to develop the projects fundamental aims and translate them into a core action plan, that hoped to not only give people with lived experiences a voice, but to see their voice and involvement transform into tangible service change. To achieve this, phase 1 of the project aimed to create a baseline of information upon which development actions and a 'co-production tool kit' for use across the region could be developed through project phase 2 and beyond.

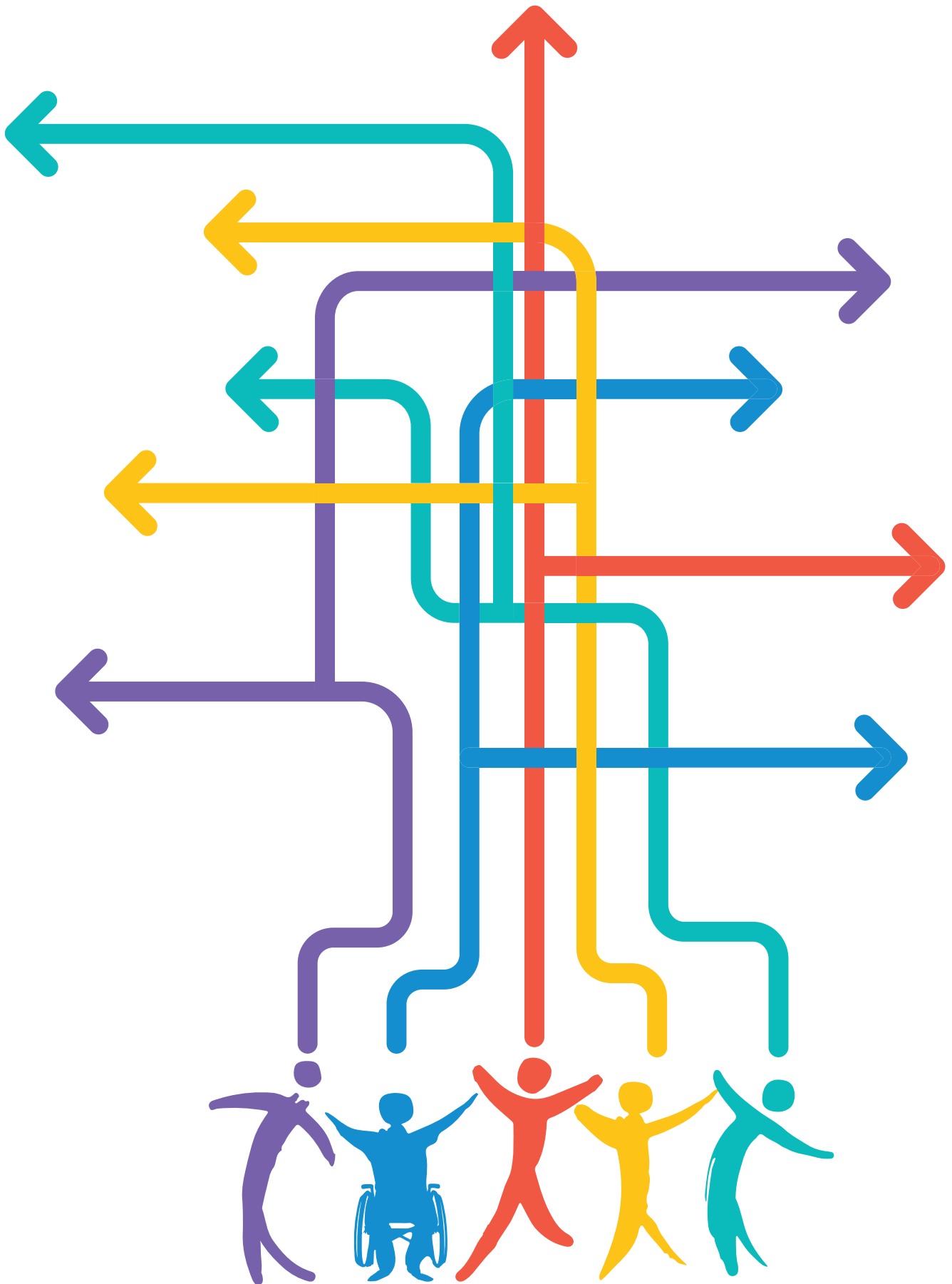
The findings outlined within this report detail the baseline information gathered through phase 1, as the project held workshops, events and engagement activities across the region with both people with lived experiences and the professionals, services, organisations and projects who work with them.

A live illustrator worked alongside the Our Voice Matters project throughout its phase 1 engagement activities and helped to bring some visualisation to the context of the conversations that were held. As part of its participatory research methods, attendees at project workshops, events and engagement activities were also encouraged to use visualisation in their feedback and input, and a combination of the two have been used to inspire the graphics contained within this report.

As the baseline data collected was analysed, four foundational themes were identified to form the structure of this report, so that the findings could be interpreted effectively. These themes are: what is co-production; the art of communication; the barriers to co-production and engagement; and offered solutions to improve the effectiveness of citizen involvement moving forward. The report concludes by recommending some key focus areas for phase 2 project development which aim to ensure that the implementation of co-production as a key priority at local and regional level can be achieved.

A total of 193 individuals were engaged through the projects phase 1 engagement activities to develop the enclosed research findings and conclusions. These individuals were made up of representatives from across the projects 5 target groups areas of people with lived experiences: Children and Young People, Older People, People with Learning Disabilities, People who access Mental Health Services and Parents and Carers, as well as staff members from the services, organisations and projects across the region who work with them.

Co-production is a Journey



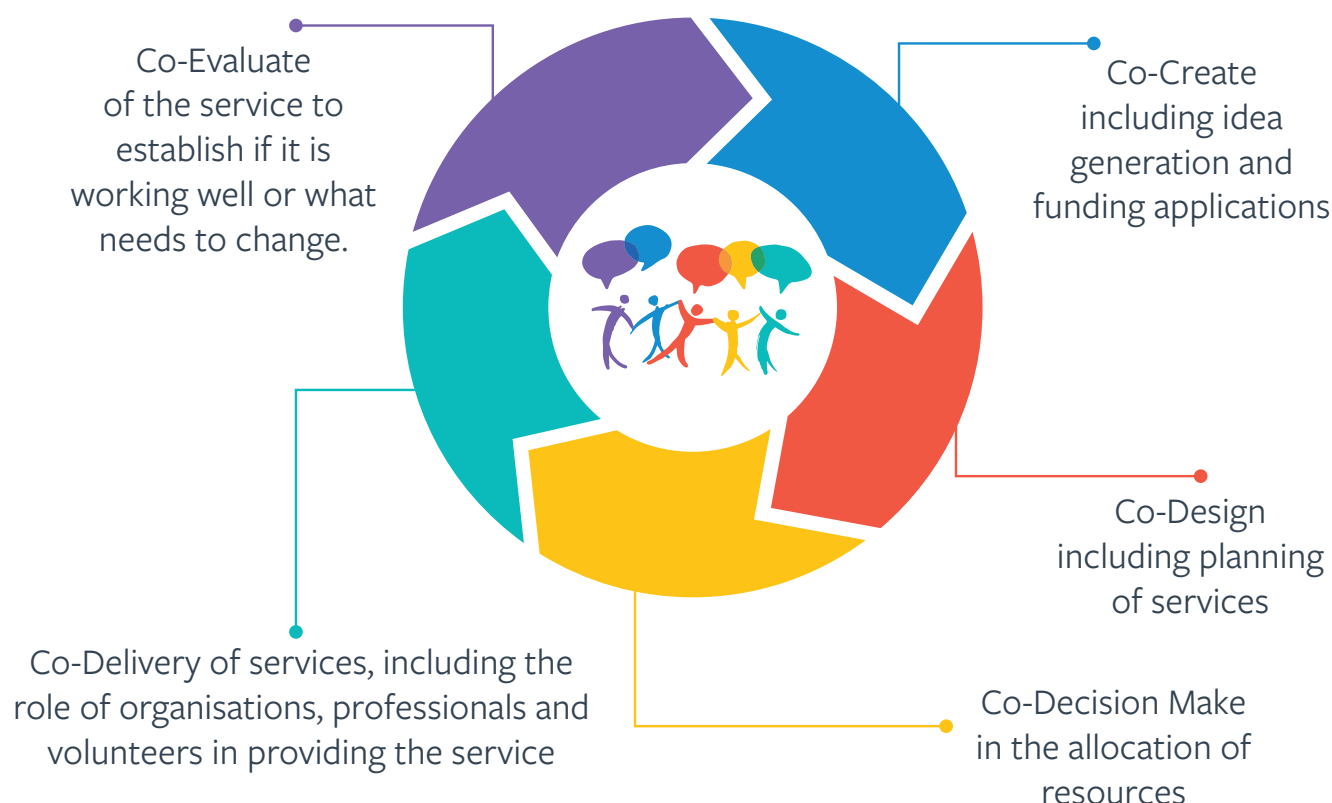
What is co-production

Co-production at its core is about re-balancing the power structure and creating a level playing field that opens opportunity for the meeting of minds to come together and find a shared solution.

In recent years it has been defined in a number of different ways to suit the desired outcome of the process in which people from a range of different backgrounds come together to discuss and make decisions about a particular issue, topic, project or service. Whilst this can be seen as a positive and reflects desired flexibility within the process, these differing definitions has also allowed for an element of ambiguity to emerge around the subject, causing confusion and making it difficult to pinpoint what good co-production looks like. As a result, both fear and unwillingness has crept into some of the crucial societal conversations taking place, leading them to

become ineffective and in some cases hostile, without any clear momentum for change.

In practice, co-production involves people who use services being informed, consulted, included and empowered from the start to the end of any project that affects them. In its basic form co-production is outlined as having 5 key elements: co-creation, co-design, co-decision make, co-delivery and co-evaluate as a framework to allow purposeful conversation to take place, outlining its importance at every stage of a project or service's existence.



The Social Care Institute for Excellence suggest that there are 4 Core Principles of Co-production that need to be considered and implemented alongside the 5 key elements stated above to ensure that the process is inclusive. These are **Equality, Diversity, Accessibility** and **Reciprocity** and each outline how the process of co-production can be strengthened, increasing its meaning and purpose, and hopefully ensuring that services are changed/improved in a way that generates benefit for all involved: Citizens, Communities and Projects/Services alike.

Co-production in Cwm Taf Morgannwg

Although the word Co-Production seems to commonly feature across the Social Care sector in Cwm Taf Morgannwg, its definition, meaning and purpose is often met with a web of confusion, fear and misunderstanding.

Through the roadshow of workshops, events and community interaction that took place during the first phase of the Our Voice Matters project, citizens and professionals were asked to summarise what they understood by this word: Co-Production. The aim of this was to generate insight into not only the general understanding of what co-production is, but the expectations and impact the co-production process has across the region.

This shows that at a basic level, co-production is understood across Cwm Taf Morgannwg as a two-way process of communication and activities that involve and empower people to share ideas and solutions based on their lived experiences and opinions in relation to a particular topic, issue or service they receive. Ideas of equality, sharing power and generating TRUST suggests that some of the key underlying principles of co-production are being recognised theoretically, however, some of this understanding is meeting barriers when being translated into practice. These issues will be highlighted under the What's Stopping Us section later in this report.



Whilst many explanations were offered to create an understanding of what Co-Production is, the top 10 words used to describe the process were:

- | | | |
|---------------------|--------------------|-------------------------|
| 1. Listening | 4. Together | 7. Trust |
| 2. Voice(s) | 5. Needs | 8. Choices |
| 3. Shared | 6. Power | 9. Understanding |
| | | 10. Equal |

Moving forward it is recommended that a regional definition of what co-production is along with some guidance of what it should look like in practice is produced to help reduce the confusion that can be associated with the term and help increase its effectiveness in transition from theory to practice.

It flows 2 ways...



it never ends...

The Art of Communication

Effective communication is a key skill across all walks of life, and as highlighted within the regional understanding, a vital component to the co-production process.

More often than not, communication is a skill we take for granted, believing it to be a basic technique that everyone is able to use without much thought or effort. However, this is not the case for everyone, especially some people with lived experiences across Cwm Taf Morgannwg, and although many citizens, professionals and decision makers would say that they are good communicators, many don't truly understand or appreciate the complexity of the art of communication.

“The single biggest problem in communication is the illusion that it has taken place “
George Bernard Shaw

“The most important thing in communication is to hear what isn't being said”
Peter Drucker

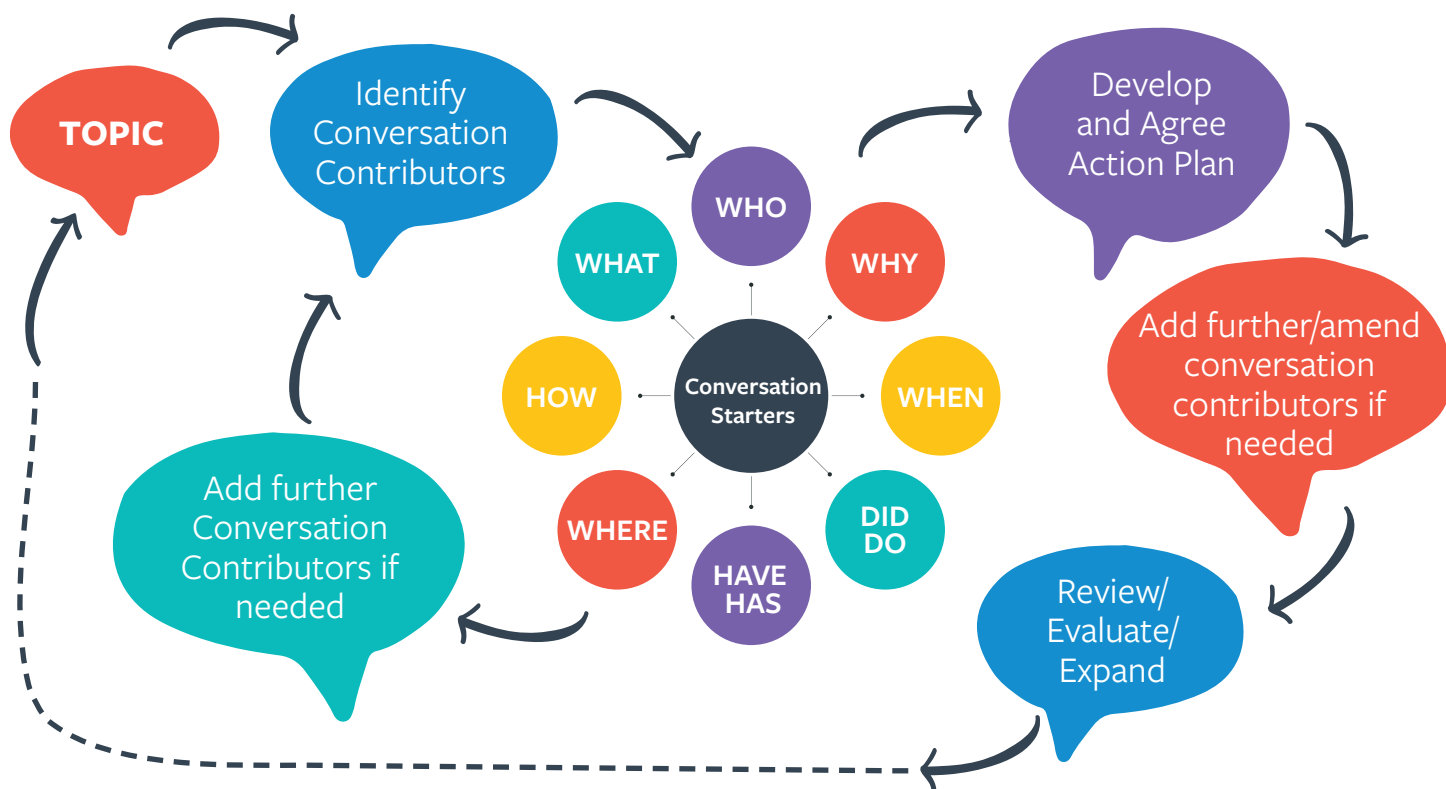
We know that for people with lived experiences across Cwm Taf Morgannwg, communication is seen as a two-way process of both speaking and listening, and through our phase 1 data collection methods this was a point that was highlighted regularly. However, for many this is also where communication issues begin, as they feel that whilst they are actively speaking and sharing their thoughts and experiences, very few people are actually listening to what they are saying, and instead seem to hear only what they want to hear. This then generates issues and barriers around trust and actively de-motivates people with lived experiences to engage fully. In situations where people with lived experiences have felt like they have been genuinely heard, another issue was commonly raised, and this related to the feeling that information flow only went one way – UPWARDS.

Many indicated that they never received feedback or were provided adequate opportunity to themselves listen to the thoughts, opinions and ideas of decision makers. Instead they felt they were often just told what to do or what was happening with little to no room for discussion or development under the guise that they had been consulted and therefore they had been included, de-valuing the true weight and intentions of their contributions, and leaving people with lived experiences feeling dis-empowered and less worthy.

As we think about the art of communication within the co-production process across Cwm Taf Morgannwg it is important to note that whilst speaking (verbal) and listening are key elements of the communication process that we all need to work on to improve the effectiveness of our conversations, they are not the only elements of communication we need to consider. In addition, we need to note and appreciate non-verbal communication and how this impacts the tone and emphasis of what we are trying to say or hear; how we word our written communication so that the receiver can decipher the correct message we are trying to portray; and our wider visual communication in relation to what images we use to strengthen the meaning behind what is being said or in some cases, not said. Therefore, as communication within the co-production process is considered, its strength and effectiveness lies within our awareness and understanding of its complexity and our willingness to keep working to improve it, learning from past mistakes and listening to feedback, whilst also offering constructive feedback to those we are communicating with.

“To effectively communicate, we must realise that we are all different in the way we perceive the world and use this understanding as a guide to our communication with others”
Anthony Robbins

Conversation Flow

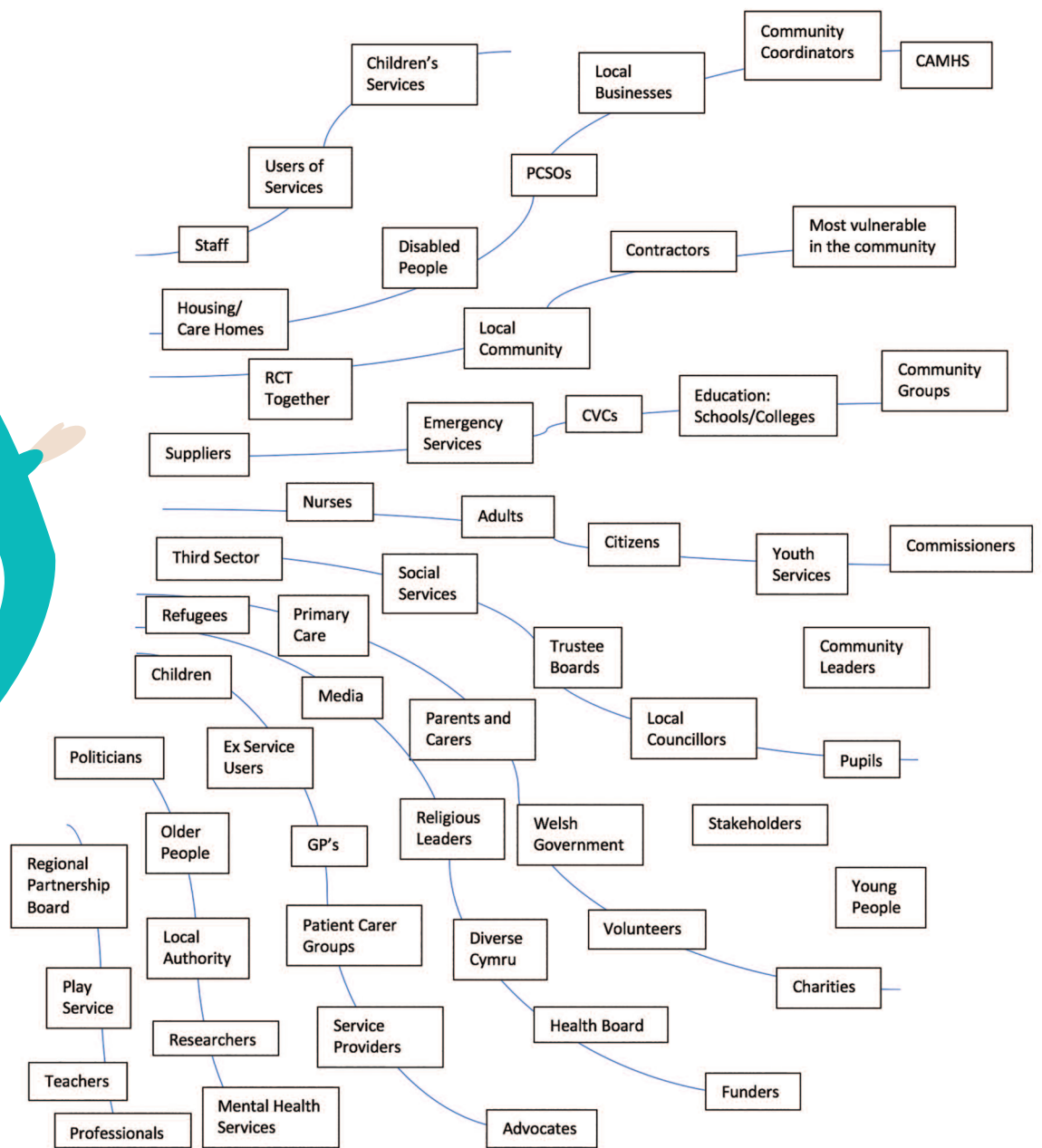
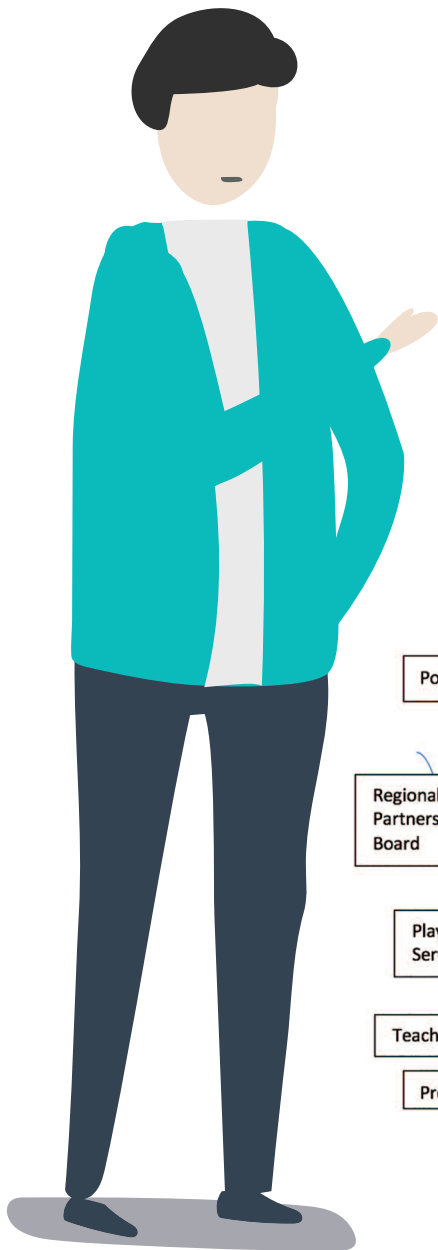


Once a basis for communication has been identified, those involved need to enter into a conversation flow to ensure that the conversation stays relevant and purposeful, developing a clear end goal and avenues for future conversations to evolve. People with lived experiences from across Cwm Taf Morgannwg have provided their top 5 tips for engaging in conversations with them:

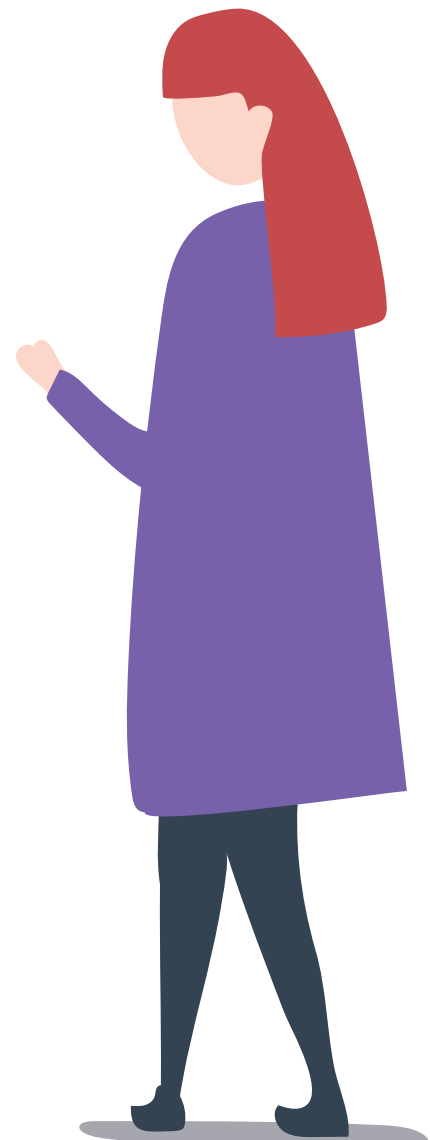
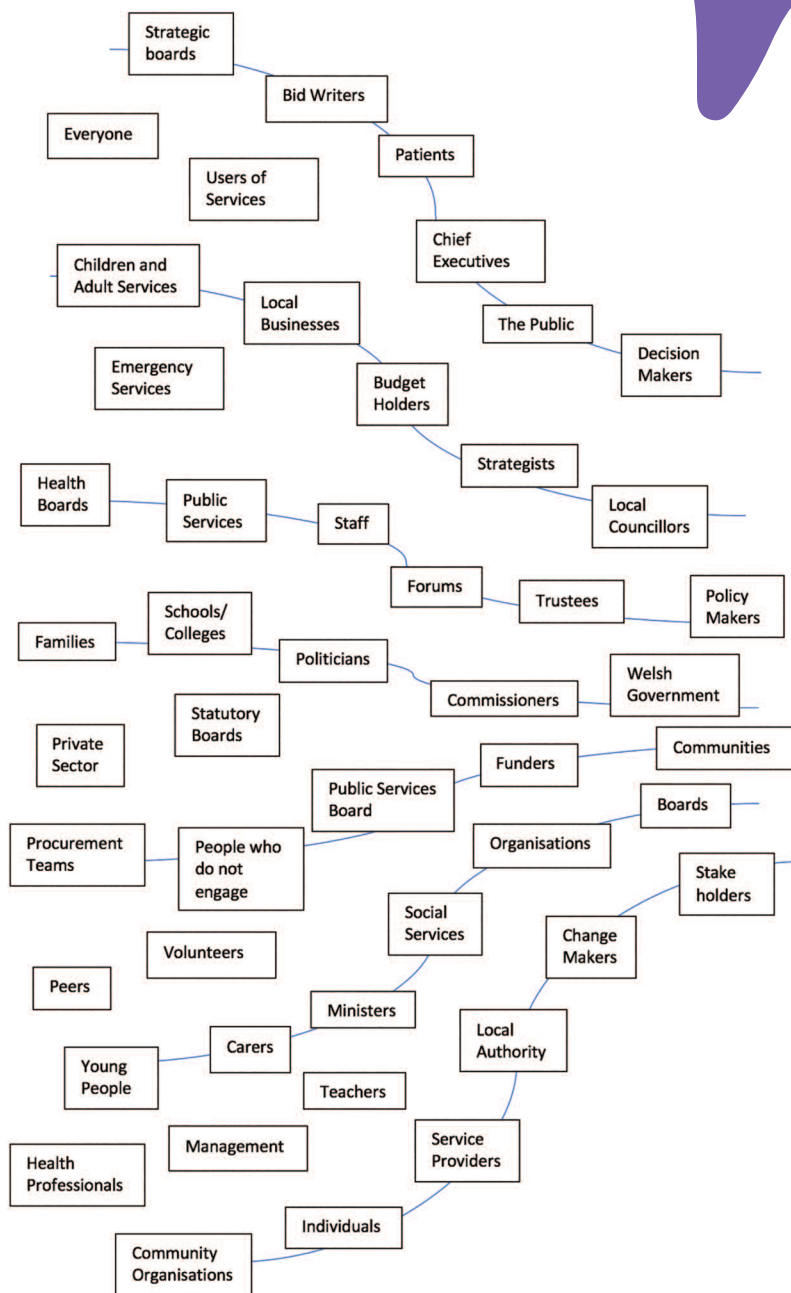
1. **No Jargon** – they need to understand what you are saying/talking about to feel they are valued and that they can contribute.
2. **Let them know what’s in it for them** – many people with lived experiences have become apathetic to the co-production process because, in their words, they tell people what they think, and nothing ever happens. Therefore, they need some incentive to be involved.
3. **Feedback** – that review element at the end of the conversation flow is crucial for keeping people with lived experiences actively involved. It also helps them to feel valued. Even when the action plans agreed can’t be fulfilled, people with lived experiences want to know what has happened with the information they have offered, and to help find solutions to problems that might occur.
4. **Go to where they are at** – don’t expect people with lived experiences to come to you, as many encounter a series of barriers that will stop them ever getting there. They need to feel comfortable and secure to help them share openly and honestly with you. Venues need to be accessible, and you need to consider the location of the nearest public transport stop. Think about who you are trying to engage in the conversation and make sure the time is suitable for them.
5. **Keep it Fun** – people with lived experiences have said that they are more likely to engage and share the truth when things are fun and interactive. They like having activities to keep conversation focused but in a way that allows them to tap into their creativity and use some out of the box thinking, to fully express what they want to communicate.

Conversation Contributors

Through the phase 1 engagement activities, people with lived experiences, as well as the professionals, services, organisations and projects who work with them offered the following suggestions in relation to the key groups of people who need to be considered as potential conversation contributors, and whilst this is not an exhaustive list it does provide insight into the diversity of contributors who could be involved in the co-production process. They recognised that some of these contributors had key roles in delivering verbal communication about their experiences and ideas for improvements, whilst others primary role is to actively listen to what is being said and then take action through effective conversation flow to develop clear outcomes for positive change.



Moving forward it is recommended that a Regional Involvement Pathway is developed as a mechanism for people with lived experiences to have a valued voice and for that voice to strengthen the work of projects and services being commissioned and delivered across Cwm Taf Morgannwg.



What's Stopping Us?

The perceived barriers to engagement and co-production in Cwm Taf Morgannwg



There are many things that can hinder an individual's ability or willingness to engage in societal activities and access opportunities available to them. No matter how good an opportunity may appear to us, there are often a host of factors that prevent a person with lived experiences participating and engaging.

As part of its phase 1 participatory research activities, the Our Voice Matters project set about identifying the perceived barriers that were preventing authentic and effective engagement and co-production work happening between citizens and professionals/decisions makers within the social care sector across Cwm Taf Morgannwg. To do this the project held a number of formal and informal workshops, meetings and events in which a range of engagement tools could be utilised to help understand why some people struggle to engage and provide insight into the barriers that freeze people out and threaten their ability to engage even when they want to.

Research findings around these perceived barriers are detailed over the next few pages, outlining the distinct differences between groups of people with lived experiences as categorised within the Social Services and Wellbeing Act (Wales), 2014

The Perceived Barriers for Children and young people



Through phase 1 of the project research a number of workshops were held to provide opportunity for children and young people to have their say on the things that matter to them, as well as outlining the

things they felt stopped them or “put them off” taking part in activities that were going on locally and regionally. One of the biggest issues that was raised by children and young people was the fact that they felt nobody really cared or really listened to them, as when they have ideas they often don’t happen, and they are not told why. Other factors highlighted included the fear and/or reality of bullying, as well as multiple barriers linked to mental health illnesses and self-resilience through low self-esteem, lack of confidence and a sense of worthlessness. Therefore, when considering engaging children and young people in the co-production process, wider work should be undertaken to explore identity, empowerment and creating a safe environment based on trust. Feedback is also important to children and young people and as such a two-way communication flow should be designed to help them feel valued and actively involved in decision making processes.

The Perceived Barriers for Older People



One of the biggest factors that was raised by the Older People engaged in the phase 1 research activities, centred around the adverse effects of loneliness and isolation. Many reported that following the death of a loved one (usually a spouse) their confidence had decreased drastically, and they therefore

participate less in community-based activities. Another key factor that was highlighted was that in some cases people didn’t know or understand what opportunities were available for them, and this was because not everyone felt comfortable using technology and recognised this was how many things were advertised. The time and day of activities were also considered a big barrier for older people, with some reporting that their confidence decreased at night, especially in relation to transport, and therefore this should be considered when identifying co-production activities for them.

The Perceived Barriers for People with Learning Disabilities



People with learning disabilities also displayed a sense of low self-esteem and low self-confidence, with feelings of being judged, treated differently, and stereotyped featuring as some of the biggest

barriers expressed. Equally, people with learning disabilities stated that they felt other people viewed them as not having any/the right skills or not having the ability to understand and therefore, they were often left out and excluded from the decision-making process. The top word to be shared by people with learning disabilities during the phase 1 workshops and research activities was the word ‘invisible’. This suggests that when co-production activities with people with learning disabilities are explored, they should focus on increasing individual value, and where necessary make reasonable adjustments to ensure people are able to effectively input and feel fully included, and seen, in decision-making processes.

The Perceived Barriers for People accessing Mental Health Services



The theme of a lack of self-confidence and low self-esteem continued for people who access mental health services. The top phase to feature for this group of people was that they were “not good enough” to take part in

co-production processes. This then led to feelings of anxiety, fear and worry, and as a result, individuals withdrawing and isolating themselves. The idea of trust was something that was discussed frequently through the phase 1 research activities with those who access mental health services across Cwm Taf Morgannwg, and the building of trust is a crucial factor to be considered when looking at future co-production activities with these individuals. Equally, wider work should also be conducted to help empower and increase self-worth and confidence prior to engaging those who access mental health services in decision-making processes, so that they can input into and embrace the opportunity effectively.

The Perceived Barriers for Parents and Carers



Time is precious for parents and carers, and alongside their caring responsibilities featured as the biggest barrier to their engagement in co-production activities. There was also a sense of apathy that surrounded

some of these discussions with the response “what is the point, nothing changes!”. Parents and carers also outlined how they felt restricted by things such as the law, policies and specific eligibility criteria that freeze’s out some people and doesn’t consider some people’s individual needs and circumstances.

Therefore, when considering undertaking co-production activities with parents and carers, accessibility is a key priority. This includes finding out what time of the day is best for people, scheduling meetings well in advance, keeping meetings short and to the point, and ensuring that they finish on time, so that people don’t miss out or feel anxious if they have to leave early. Parents and carers also value feedback and like to see momentum pushing towards changes so that the process and their involvement in it is seen as worthwhile.

The Perceived Barriers for Services, Professionals, Organisations and Projects



As part of the phase 1 research activities, the Our Voice Matters project also wanted to consider some of the issues and barriers experienced by the services, professionals, organisations and

projects who are working with people with lived experiences. Whilst there was an appreciation for the barriers that have been expressed by the five above categories, additional factors were outlined by the individuals within this group. These additional factors had a more strategic feel to them and included things such as GDPR, Legislation and Funding. A lot of discussion was held about issues relating to funding, especially short-term or limited funding, and how this impacts the sustainability of services and projects. Services, Professionals, Organisations and Projects have suggested that longer-term funding will help to make sustainable positive change by allowing them to understand individual needs and experiences in more detail, and therefore design and deliver services in a more co-produced and person-centred manner.

Breaking down the wall

Whilst it may feel impossible to overcome all the perceived barriers that have been highlighted, it is important that we do as much as we can to make reasonable adjustments to open up the capacity for engagement to as many people with lived experiences as possible.

The strength of our services comes from the diversity of experiences that feed into the process, to help us consider the things we are doing from a range of perspectives. Taking time to break down some of these walls may seem like hard work, but the results it will produce has the potential to save both time and resource in the future, allowing us to get things right the first time, as well as to continually evaluate and improve things as we move forward.



Solutions Hub

As well as identifying the barriers that stop people with lived experiences engaging in co-production activities across Cwm Taf Morgannwg, phase 1 provided people an opportunity to consider and share their solutions to overcoming these barriers and improving the effectiveness of co-production in the future.

Opportunities were offered for people with lived experiences to share their personal thoughts and opinions in regard to potential solutions as well as engage in group work activities that allowed collective thought sharing and idea generation to develop. The solutions offered across these pages bring together the numerous solutions of people with lived experiences, as well as the professionals, services, organisations and projects that work with them, analysed through a grouping method to identify the common themes. These themes provide some interesting food for thought as we think about how to translate the willingness and desire of co-production in theory from a strategic viewpoint, into an operational reality of the way professionals, services, organisations and projects work on a day-to-day basis.



We need to create a way for regular feedback and feed-forward to happen to keep people in the loop and continue a solutions focused drive to any issues that might be encountered along the way – this will help keep the momentum of any project, change or conversation.



We need to think about pre-engagement activities with people with lived experiences that helps them to build the necessary skills, capacity, understanding and resilience to be effective within the co-production process.



We need to develop an understanding and appreciation that change is a process, and that all involved, including people with lived experiences are considered as equal change makers and are empowered and authorised to get the job done by embracing all the elements of the evolving nature of an authentic change process.



We need to recognise the skills of the voluntary sector in engaging with the local community and with people with lived experiences, and statutory sector partners need to use them as crucial allies in helping bring people to the table, as well as value the insights such organisations can offer in developing a wider understanding of an issue within the co-production process.



There needs to be more training for all conversation contributors, not just people with lived experiences, about how to communicate effectively, what does change look like, how to embrace a culture shift and what to do with the information gathered within conversations. This training should be based on a regional approach to co-production so we are all working towards a common goal and guidance should be produced to help everyone involved fully understand what is trying to be achieved.



We all need to be brave and not be afraid to fail. Failing = learning = growth and by discovering what doesn't work, we are one step closer to finding what does!



We need to make sure that everything we do is accessible and that people with lived experiences know about it. Think about their top 5 tips for successful conversation: no jargon; let them know what's in it for them; feedback; go to where they are at; keep it fun. Some groups of people with lived experiences may need further reasonable adjustments to be made to ensure accessibility. This might include Easy Read information, translators, the use of visual aids etc.



Location of meetings, times of meetings and transport need to be considered to help people with lived experiences engage, as these can often be barriers that hinder them.



There needs to be recognition that sustainable change takes time, and value needs to be given to the full change process from start to finish. To ensure sustainability, services, organisations and projects need to be able to see the change process through to completion, and therefore require longer-term funding to embed the outcomes of co-production into practice.



We need to be better at sharing good practice examples and be willing to learn from each other. The commissioning structure needs to be reviewed to stop pitting services and projects against each other and instead promote more collaborative working. This will help everyone to bring their specialist skills to the table so that issues are tackled holistically.



Case studies should be used to not only showcase good practices and celebrate success but as a learning tool so that we can learn from each others mistakes. Services, organisations and projects shouldn't be afraid to admit when something hasn't worked as planned so that others don't have to repeat their mistakes.



We need to generate accountability for the co-production process to ensure it is valued. Local and regional policies and procedures should be reviewed to develop this accountability structure and ongoing review/evaluation of services, organisations and projects should be conducted as part of the commissioning process.



Services, organisations and projects need to move away from a culture of 'following the money' and instead look for money to fit the projects that meet the needs of those they are working with. Funding bids should show evidence of need and funders should consider and value softer outcomes that allow demonstration of personal growth and journey, rather than statistical data – we should be focused on quality over quantity.



There needs to be some form of good regional analysis undertaken periodically to assess the evolving needs of people with lived experiences and to change priorities accordingly. Flexibility within the system is key, and any needs changes identified should be communicated effectively to maintain the common goal approach.

Conclusions

Keeping people with lived experiences at the heart of everything we do!

The biggest take away from the phase 1 research is that people with lived experiences, professionals, services, organisations and projects across Cwm Taf Morgannwg want to be involved, and there is a real sense that everybody wants to find a way to do this effectively. There are many segments of the co-production process happening across the region, with some being more effective than others, however, there does appear to be a missing link for information to flow effectively between operational level 'ground-work' organisations and the strategic decision-making bodies. There also appears to be a missing link between statutory services and third sector/voluntary organisations, resulting in a missed opportunity for information sharing regarding needs, tried and failed practices, and tried, tested, succeeded and sustainable ones. Therefore, one of the main priorities as we move forward together has to be the development of recognition of others (organisations, projects, communities and people with lived experiences) as equal and valued contributors to the process, with something of worth to provide. This joined-up thinking and collaborative working will not only make the co-production process, and ultimately service offer and delivery across the Cwm Taf Morgannwg social care sector more effective but will reduce the level of duplication and ineffective practices across the region.



To make a positive start towards the development of a 'common goal' and shared appreciation for the co-production process, we need to identify some key regional understandings that will shape the way everyone across the sector works together. This must begin with the identification of a singular definition of co-production to help reduce the levels of fear, misunderstanding and confusion associated with the term as identified through the phase 1 engagement activities. Equally, work needs to be done to overcome the various barriers people with lived experiences and the professionals, services, organisations and projects have identified that stop them being able to effectively contribute to the co-production process, involving a diverse range of contributors in the development and planning of solutions.

Together, services can be changed, needs can be met, and people with lived experiences can take a level of ownership over their lives. Co-production is more than just a buzz word. Co-production done properly works. So let's make it OUR priority to do it right!

End of Phase 1 Recommendations

Following a comprehensive review of the information gathered throughout its phase 1 research, the Our Voice Matters project has developed the following 5 recommendations to advance the effectiveness of co-production practices across Cwm Taf Morgannwg. Careful consideration has been given to the solutions offered by people with lived experiences and the professionals, services, organisations and projects who work with them in the development of these 5 recommendations, with the hope that a diverse range of contributors will be willing to engage with the Our Voice Matters project to see them completed through its on-going work with the Regional Partnership Board.

- 1.** The development of a co-produced regional definition for the term 'Co-Production'.
- 2.** The development of a co-produced regional commitment towards Engagement and Co-production.
- 3.** The creation of a co-produced regional guide to Engagement and Co-production principles and tools for implementation across services and projects in the overcoming of perceived barriers and to increase the effectiveness of these principles in valuing the voices of users of services/people with lived experiences.
- 4.** To work towards the creation of a regional involvement pathway that develops a mechanism for people to have a valued voice and for that voice to strengthen the work of projects and services being commissioned and delivered.
- 5.** To develop regional co-production criteria for the commissioning/funding of future projects and services, to be included as part of the funding application process.

**SHAPING
SERVICES
TOGETHER**



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