CASE STUDY 3: BETTER LIVES: WORKING CO-PRODUCTIVELY IN GWENT IN LEARNING DISABILITY SUPPORT

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1. BACKGROUND: WHO WAS INVOLVED

The main driver for the Better Lives project was that people with learning disability generally have poorer lives. The project is driven by people who have a lived experience of a learning disability; wanting to look at ways to change their lives. In recognition of the Social Services and Well-being Act, 2014 they considered doing things differently on a regional basis (Gwent-wide) within adult learning disability services. There was an initial perception and concern that the Act meant losing services rather than creating them by and for people who needed support through co-production. Whilst, easy read versions about the Act are available, it was felt that people with a learning disability did not know much about the Act and the opportunities the Act would provide. In response to the Act, a post of Innovation and Development Manager: Alternative Service Models was created funded by the Integrated Care Fund to begin the research process. The Manager began work initially in Torfaen and then across Gwent, which transformed into a co-productive approach in spirit and action to develop what mattered to people living across the region. The project brought together groups from the People First movement across Gwent, particularly Torfaen People First and Barod CIC to take forward the project. It was important that those involved understood the concept co-production and that engagement and partnership working where ‘rungs down the ladder’ of participation. People with a learning disability were the central driving force for change throughout the project, asking other people what they wanted to happen, and the types of services needed in the region to meet their needs. The Manager approached representatives from Torfaen People First, but there were a number factors, which were important to secure their support and time:

- Being on equal terms with council officers
- Being paid for the work asked of them for the benefit of Torfaen People First.
- Being valued for their input.
- Group decision-making and having support to carry out their role in the project.

2. KEY THINGS ABOUT THE PROJECT

- No pre-conceptions about what mattered to people and what services needed to be commissioned.
- Paying people to carry out the research on what matters to people with a learning disability.
- Having an equal say about how the money earned by members of Torfaen People First would be spent.
- Not relying on goodwill, but that goodwill was important to develop trusting relationships between people.
- Knowing why it was important to undertake the research: what it meant to those interviewing and those being interviewed.
- Working with people’s strengths and recognising when there was not the capacity and time to be involved.
This project was ‘very much shared’ and that it did not belong to anyone; it was a collective of people across sectors who seek to find out what people wanted by asking them directly to ‘see where we can make a difference….it’s not about ego or organisations, it’s just about what will make it work’ in meeting the support needs of the learning disability community in the future. From the outset it was notable that the Innovation and Development Manager was a co-productive practitioner. He spread his enthusiasm and was trusted, which supported the enablement of representatives from Torfaen People First to be active in finding out what other people with a learning disability wanted. The most crucial factor was that a different approach was taken to be inclusive; that there was equality and those who were to be the researchers were paid for their time as their council staff and third sector colleagues and was the outstanding feature of this project. There was an equal say as to how the allocated budget would be spent.

The research process worked well by:

- Designing a research process which was accessible and agreed.
- Developing the questions to ask people and consulting on those questions with people, other groups and organisations.
- Working as part of a team: Working with people’s key skills and strengths to collect, collate and analyse the results together. Members of Torfaen People First did the initial coding rather than someone else interpreting the data they had collected.
- The interviewers knew many of the people they were interviewing which helped to support people to respond, without bias, as the questions had been agreed through consultation.
- Not making assumptions about what people wanted.
- Whilst, not everyone answered all the questions, over 100 people took part.
- Agreeing together the themes and the projects to be designed around those themes.
- Producing posters outlining the key themes so that everybody understood each theme.
- Held a conference based around the 5 themes to explore further ideas.
- Not letting the research ‘go into a black hole report’ and stay on a shelf not used.
4. THE 5 KEY THEMES: BETTER LIVES

The evidence from the interviews formed into 5 key themes, from which specific projects were developed, based upon what support or services people wanted to see happen. The Better Lives project wanted people to know that:

- It’s my life: Let me get on with it, I will live with whatever happens.
- It’s my life: It’s my money, I can use it how I want.
- It’s my life: I want a job, I want to be paid.
- It’s my life: I want to go out with my friends.
- It’s my life: Sometimes we want to be alone

Subsequently, a conference was held designed and facilitated by members of the People First community based upon the 5 key themes. People were asked to make a pledge as to what they could do to support the work. However, people had many ideas and things they would like to change. It was highlighted that one participant never had any of her own money even to pay for a cup of tea. All that change, by one simple action, when she was given some cash so she could buy her own tea and was ‘thrilled about it because suddenly she was in control of that’. Decisions needed to be made about which of the key themes to take forward; the main messages people wanted to let people know about. Those decisions were made together based upon what was possible to initiate, drawing upon the skills, time available and capacity of those taking part.

Going out, meeting friends and being able to feel safe in the community where the top priorities. Safe Places was launched as product of the of the research and was the most straightforward to initiate. Training was provided for people to ask shops in a local town centre why a safe place was needed for people. Well-known retail shops, banks and local businesses were invited to an open day to find out about the Safe Places project. Shops, banks and businesses were asked to display a Safe Place sticker so if a person felt anxious or became lost and carried a card or
key fob with 2 contact telephone numbers, the shop could make a call on their behalf. This project worked well, people worked as a team and decisions were made jointly throughout. Safe Places has now spread to other locations across the region as an additional outcome.

The Gwent Charter was launched on 25th April 2018 at an event to celebrate it through music, drama and a premiere of a film about the Charter. The Charter was developed by People First members across 5 groups. The Charter is based upon the 5 themes and seeks both organisations and individuals to sign up and use the Charter in practice. A group of paid Charter Checkers will monitor and check to ensure that those who have signed up keep to the intentions of the Charter. Information, training and support people to use the Charter will be provided. Overall, the main intention of the Charter is to ensure their voice is heard.

5. WHAT WAS LEARNT

Time and capacity: Torfaen People First felt it was important to recognise what was possible for them to contribute to Better Lives once the key themes and potential projects had been identified. Members felt that, at times, it was quite time-consuming interviewing people and that they wanted to ensure that they had enough time to carry out their roles effectively, without it becoming too onerous.

Recognising people's strengths and skills: Importance of paying people was paramount, in recognition of the strengths and skills they brought to the team. The 5 People First groups brought different types of knowledge which gave the project dynamism and depth. People felt they ‘were at the centre of it and treated equally for the strengths and skills they brought to the team’.

Helping people to dream: Some people interviewed struggled to express or visualise what mattered to them. It was felt that they needed ‘permission to dream’; deferring to what they thought people expected them to say. However, the interviewers had prompt sheets with pictures of activities to act as a ‘dream trigger’. Once one person began to express their hopes and dreams it created a chain reaction of dreaming. The interviewers could ask a prompt question to gather more information once people began to express what mattered to them and what they wanted in the future.

The research: It was important to return to the research, to ‘say what it was for’ and where they could make a difference across the 5 themes and how effectively to use the data.

Working as a team: Team working and being able to trust the Innovation and Development Manager was a central feature. Being co-operative, removing competition, with professionals and organisation letting go and sharing the power and decision-making processes has been a continuing feature for People First groups across Gwent and for local authority and third sector colleagues involved in Better Lives.

Working together through Better Lives has:

‘Brought closer connections….and that the People First groups are now tighter than ever, there is a lot of joint working going on’.
Better Lives identified several outcomes beyond the original intention project. A final report was produced setting out how they would address the 5 themes through initiating a series of projects. However, the following additional outcomes were:

- **Being co-productive:** Embracing the principles of co-production was a crucial outcome. That *its empowering….because some of the traditional systems people are “done to” and their voices are not heard in it and they (people with a learning disability) have very little power*. Shifting power dimension towards equality and people driving change was supported by people getting paid. This was a *‘big step forward….and having an equal say about how to spend the budget’* rather than a top-down approach to commissioning; *‘you can have a bit on money to do this bit and you can have a bit of money to do that’*, which had been the previous experience. The joint work undertaken has triggered an ethos of co-production across Gwent.

- **Changing commissioning practice:** It was felt that Influencing what happens, from a commissioning perspective, *‘makes you think bigger’* and provided the opportunity to think about what is possible to achieve. The Gwent Charter will be included in contract specifications. Organisation aiming to provide commissioned services are be expected signed up to the Charter. Importantly, commissioning in a different way, where what matters to people was the catalyst and stating, *‘these are the services we want you to commission’*, rather through local authority-imposed contract specifications where the co-productive design of services was absent, is a key outcome of Better Lives project.

- **Full cost recovery:** People First being paid for conducting the interviews and being Charter Checkers led to discussions about how to cost realistically their time to ensure that they did not feel taken advantage of or grateful to *‘have a seat at the table’*. Previously, they were providing free training. They considered the market training rate and felt that to charge under the rate people would devalue their work or the training they delivered. Pan-Gwent, the People First Groups agreed a training rate to limit the competition between groups so that work could be shared across the region and beyond.

- **Improved confidence:** People First group members of the team grew in confidence. They felt able to challenge their professional colleagues when they considered they were making judgements about the evidence from the research they did not agree with or when deciding the key themes unilaterally. Confidence grew individually through taking part in the interviewing and analysis process. People First members facilitated a conference based upon the 5 key themes and had the confidence to speak to the audience. One team member moved into her own supported living home and two other People First members felt more confident to start thinking about living independently.

**Key Point:**

**Working out what skills were needed, finding people to fill any skills gaps, and learning new skills from each other as we did the work was an important outcome of this work.**

**Postscript:**

- No More Barriers has begun to address employment issues.
- Digi connection is connecting people through technology.
- 2 Gwent ambassadors (people with lived experience whose brief is ensure people are involved in plans about them).
7. Conclusion

In brief, the Better Lives project has been and continues to be influential in using and promoting a co-productive approach across Gwent. Co-production has led to more innovative practice in the commissioning of learning disability support. Crucially, People First group members, who were part of the team, felt that they were on equal terms with professionals as they were paid for the work they undertook. Group decision-making as to how to spend the money they had earned, for the benefit of the People First movement across the county, was important to them. They felt more valued and appreciated and trusted the professional members of the team who were accessible and reliable. Significantly, the Innovation and Development Manager was the ‘trusted maverick’, who was steeped in the principles of co-production and person-centred practice. He was not only trusted by members of People First, but also by other colleagues who gave him the freedom to help facilitate the development of Better Lives.

Finally, the co-produced research design and interviewing processes helped ‘people to dream and once you start realising that people need to be helped to dream’ their ideas about what really mattered to them came through about what they wanted for the future and helped towards agreeing which pieces of work to take forward within the Better Lives project. Safe Places, as a concept, has now spread to other vulnerable members of the community through use of the card or key fob in many towns in the region.

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