The Bridge Project

Interim research findings - April 2019

Contents

Introduction

The Bridge is a two-year research project looking at how people with learning disabilities can have real work for real pay.

We are learning about four outcomes:

- How self-advocates can get real work
- What changes when self-advocates see themselves as workers
- How self-advocacy groups can become more independent by trading
- How being more business-like changes how self-advocacy groups are viewed.

The Bridge is funded by Big Lottery through the Disability Research on Independent Living and Learning (DRILL).

What is this report for?

This report is

- An evidence base for people who want to try to achieve the four outcomes above, and
- Information for people who want to change the way things are at the moment.

We have done the first year of research, so this is an interim report. We will do another report when the project is finished.

Which parts should I read?

This report starts with a section to give you the background to the research: why we have done the research, what we have done so far and our plans for the next year.

Next, the report has sections on different things we have learnt so far. They are divided up into things about people and things about organisations.

At the end there is a section with more detail about how we have done the research.

In each section there are blue boxes with more detailed information and green boxes with examples or case studies.

Background

Why the project is needed (the problem)

Fewer people with learning disabilities are employed than people in general. This happens even when there is a lot of money spent on supported employment and getting ready for work.

We want to find out how people with learning disabilities can get real work and real pay.

Self-advocacy groups help people to live independently and to develop their skills. These groups get less funding now and are relying on grants and their local authority for funding.

"It's really hard for us to have enough money" (Trustee, MLMC)

We want them to develop business ideas to earn money to keep the group going and to provide employment for self-advocates.

There are barriers, hurdles and potholes in the journey to employment for self-advocates and the journey to financial sustainability for self-advocacy organisations.

We want to find these problems and see if we can solve them.

Box 1.

Independent living relies on strong self-advocacy. People with learning difficulties often have less opportunity to develop self-advocacy skills. Strong self-advocacy is easier where there are strong self-advocacy organisations.

Currently very few self-advocacy organisations generate significant income from their activities. Most rely on grants or service level agreements, and most are financially vulnerable. A significant number have closed in the last couple of years, particularly in England.

While business advice is available, organisations do not see themselves as businesses or social enterprises so do not look for such advice. Even if they do (as Barod did), they find the advice is too difficult to understand because of the language and unfamiliar concepts, or not obviously relevant to their situation. This means many organisations are failing to capitalise on their potential to earn unrestricted income.

We want more people with learning difficulties to earn money from socially valued work. Sometimes self-advocates are paid for delivering their organisation's training or other services, but usually less than £20 a week, rarely towards the higher end of permitted work payments and it is even more rare to be paid to work 16+ hours a week. Many work for free.

This common experience within self-advocacy organisations is similar to employment experiences in general for people with learning difficulties. It is rare to be paid to work 16+ hours a week. The often-quoted figure of 6% (Mencap website) and lesser-quoted figure of 17% (Emerson) includes those working for one or two hours a week; the percentage working 16+ hours is below 2% (30.7% of those working, Mencap website). There are many organisations tasked with helping people with learning difficulties into employment or self-employment, but they have limited success.

What have we done so far (our approach)

We have set up a partnership of five organisations.

Three are self-advocacy groups that have run pilot projects
- Carmarthenshire People First – CPF
- My Life My Choice - MLMC
- People First Dorset – PFD
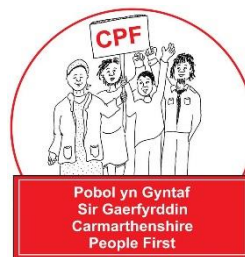
One is a business support organisation
- Social Firms Wales – SFW

One is a social enterprise that employs people with and without learning disabilities and does research
- Barod Community Interest Company - Barod

We started by having a meeting of everyone to get to know each other and to find out about doing research and how to do Action Research. We call these meetings Big Thinks.

The self-advocacy groups decided on a business idea to develop. Barod and SFW met each group and talked about how to start it off. The groups have worked on their idea using the Action Research cycle (Picture 1).

As the groups have worked on their business idea, they have recorded the decisions they made and the work they have done. They also recorded what has worked or not worked and personal reflections on their experience.

As the business ideas have progressed we have had two more Big Think meetings (Picture 2) to discuss important ideas and to collect research information.

Picture 1: The Action Research Cycle
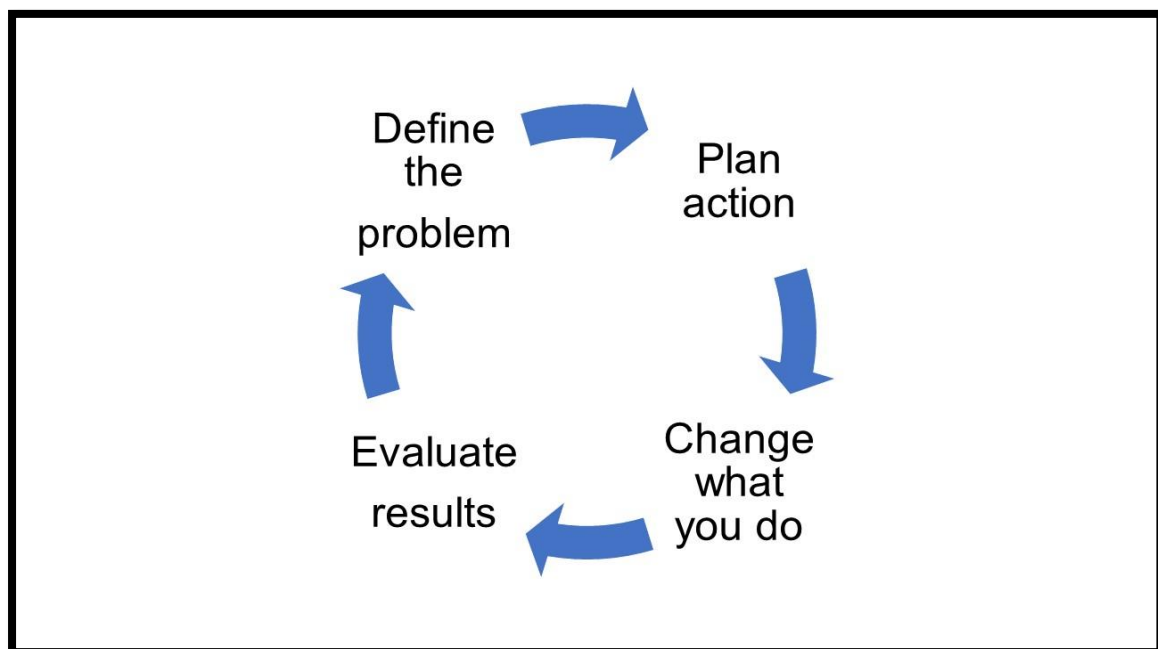
Picture 2. Working together at a Big Think

(written or video) of the development to supplement the review/planning meeting record. This will include recording perceptions of changes in attitude (their own, others in the team, and customers/partners/ supporters)

To understand, test and disseminate the ideas emerging from the pilot partners, there will be four 'Big Think' events where a wider group of people gather to consider the learning, test it against their own experience, provide feedback for the project partners and take the learning away with them to apply in their own context. Barod and Social Firms Wales will facilitate these meetings, record the discussions and outcomes, and turn the learning into workbooks and guides, assisted by the pilot partners where necessary.

Case studies illustrating the learning will be collated from individual diaries, records of review/planning meetings, additional interviews and analysis of the pilot partner performance data (success of the business idea in financial terms, employment or self-employment of members and any milestones agreed by the pilot partners).

The co-researchers in Barod and Social Firms Wales will also keep reflective diaries, documenting their perceptions of the business models that are emerging, any insights that may add to the learning, and any changes in practice that they undertake.

Where users of the workbooks and guides receive mentoring, this will be recorded in standard templates to provide a record that will be analysed to demonstrate the wider impact of the action research and to consolidate any learning.

What is planned for next year

We will continue to develop the business ideas. We will also test and produce business development tools based on what we have learnt.

To back up and add depth to the findings we will collect case studies of self-advocates that have been involved in developing the business ideas. These will be videos and leaflets or pages on a website.

We also want to see if there is a need or demand for a network of self-advocate led businesses, and to launch that network if it is possible.

We will have a final Big Think in September and then a conference to tell other people about our findings in December.

Pilot partners may also run a local event to promote the findings.

Interim findings: self-advocates

We found that getting involved in a business was a big thing for self-advocates. People had expectations about what it means to be a business person that needs to be checked against reality. We found barriers or potholes in the journey to starting a business and some things that helped. We found that as you develop a business. how you see yourself and how others see you changes. We also looked at what happens with benefits when you start to earn money. Finally, one group had some self-advocates who wanted to become self-employed and we have some ideas about what is needed to help them.

Checking expectations about starting a business and reality

Self-advocates had different reasons for getting involved in the business ideas.

- Four self-advocates wanted to set up their own business
- Five self-advocates were already involved or wanted to be involved in leading a project/activity in their organisation
- All the self-advocates wanted to develop their lives and skills, but didn't know how
- Some wanted to have ownership of the business (so they call it theirs)
- Some wanted more control over their lives
- Most wanted to say they were working
- They wanted to take control, making their own decisions about the business

More generally, self-advocates said that they want to work to meet people, have their own money that they have earned (rather than being on benefits), have a sense of self-worth, be like other people, feel useful, get a feeling of achievement, have a reason for getting up in the morning and to be motivated.

The three self-advocacy groups had different stories about how they got involved.

CPF joined the project and had several business ideas and other projects, but when the Bridge funding was approved they thought it would be useful to support and look at some members who were beginning to start their own businesses as sole traders. They asked people who might be interested, and four volunteered.

When Barod told PFD that the Bridge grant had been approved, they already had a problem that the Bridge might help solve. They had funding from their local authority for a quality checking service for day opportunities. However, this funding was going to be stopped, so they had the idea of turning a funded service into a self-supporting business. Two self-advocates were already employed in the leadership of the quality checking service, so they were involved in deciding to turn it into a business.

MLMC have a project called 'Power Up' that provides training to self-advocates to improve their advocacy skills and also has a number of self-advocates that provide that training as well as provide training to outside organisations. This has some core funding but has potential to become self-supporting or even income generating. It is coordinated by a staff member but involves two MLMC champions who are employed by MLMC. In addition, some other newer members were recruited to help develop Power Up into a business.

As the self-advocates looked into becoming workers or running their own businesses, they were aware that things would change. Some of these changes were welcome, but they were unsure about other changes or beginning to see them as problems.

The self-advocates thinking about becoming sole traders became aware that they needed to be committed to their business, that it would need a lot of time, that it would need determination and that it was risky - it might not work. For one self-advocate who did a lot of volunteering if the business was to be successful, she would need to reduce the amount of volunteering. For another self-advocate, turning a hobby into a business meant changing how he thought about his hobby, which was not easy.

For those who already worked, they currently worked one or two days a week. If the business was to take priority, they might need to work more hours. For

some this was OK, but for others it would mean less free time, getting up earlier on some mornings or seeing their friends less. There was also the worry that they might 'burn out' if they worked full time.

Things that got in the way, and some things that helped

As we supported the new businesses, we talked about the journey and the potholes participants had seen or fallen into, and how they had got over them or out of them.

Some of the potholes were **personal concerns or issues**

- worry about whether the business will work or not
- worry about benefits (one participant has had benefit issues)
- worry about the time needed to do things (no-one has yet stopped because they have no time)
- illness (is this more likely for people with learning disabilities?)
- getting others to agree to the plans
- changes in support or their team

Some responses to these were

U-turns - deciding to change direction
- one self-advocate was very challenged by changes in personal circumstances and illness. This has led her to put her business ideas on hold. Her health is more important than the business.

Bridges - things that you can do before you meet the pothole
- several self-advocates talked about having a positive attitude to change
- both projects have had more than one member of staff involved to give continuity
- a self-advocate has spoken with Housing Benefit and Disability advisors before accepting additional paid work to make sure it would not have an adverse effect.

Ladders - things or people that help you get out of a pothole
- several self-advocates have needed emotional support when they have expressed worries or doubts.

Leaps of faith - actions by the person to overcome a pothole
- one self-advocate talks about coming off benefits as a leap of faith.

Some of the potholes were **things that happened.** Here we look at things which happened to self-advocates developing their own businesses.

- practical issues, like equipment breaking or suppliers letting you down
- legal issues, finding out there are some things that you are not allowed to do
- needing to have insurance
- marketing issues, not knowing how to find out if there is a market, not knowing how much to charge, having poor responses to a survey, wondering what the market research means
- product issues, needing to describe the service or product you are selling, needing to develop prototypes and check them before any money is paid (Pictures 3 and 4)
- financial issues, how to keep records, what is a fair wage, how will the new work affect the benefits of self-advocates, how do we work out what it costs
- people issues, how to work with others
- time issues, how to deal with conflicting priorities, how to manage your time
- learning to develop a business, understand business jargon, making decisions with a business advisor

Some responses to these were

U-turns - deciding to change direction
- the card making business cannot use Disney characters because a license is too expensive.

Bridges - things that you can do before you meet the pothole
- One self-advocate has done some practice events to test out his business idea, some paid for and some free
- self-advocates and sole traders have been shown how to keep a record of income and expenditure

Ladders - things or people that help you get out of a pothole
- a sole trader has asked for help to know which insurance he needs to sell things at a craft fair
- one sole trader has asked for help to describe what his services are, and how to price them
- one sole trader was supported to develop an easy read feedback form so she could check if people liked her chutney
- one sole trader showed resourcefulness and resilience when equipment broke and suppliers let him down
- one self-advocate has been supported to organise his time to meet different objectives
- one sole trader has responded to customer feedback by changing aspects of the cards that he sells

Leaps of faith - actions by the person to overcome a pothole
- buying equipment and materials you need (eg a camera or ingredients for chutney or card making materials)

Picture 3. Recording actions from a review meeting
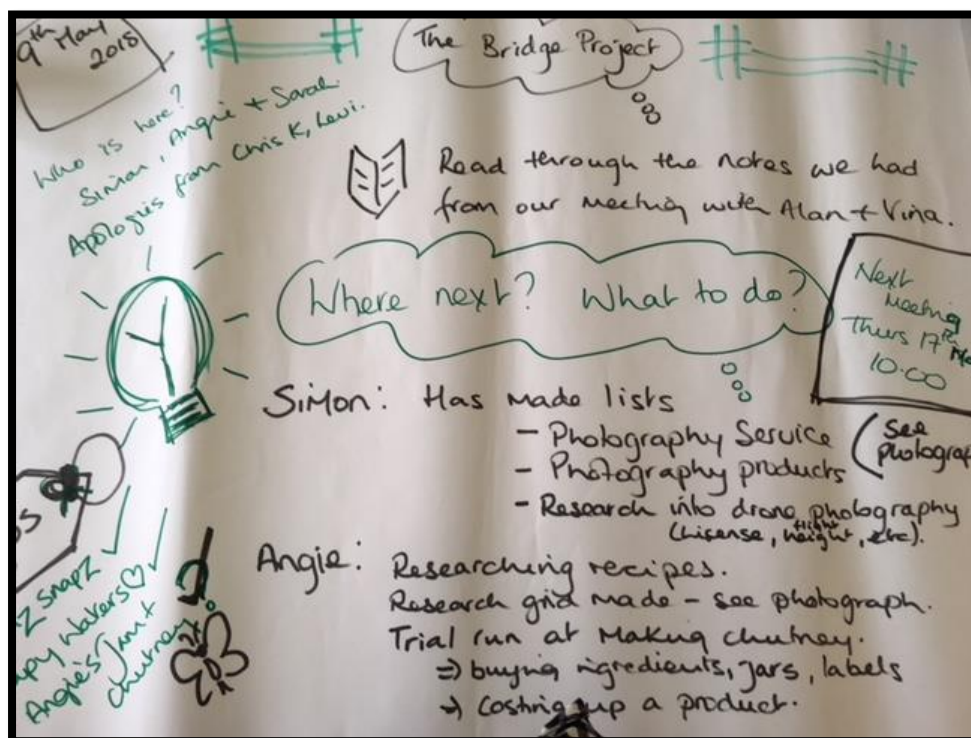
Picture 4. Catching up on progress
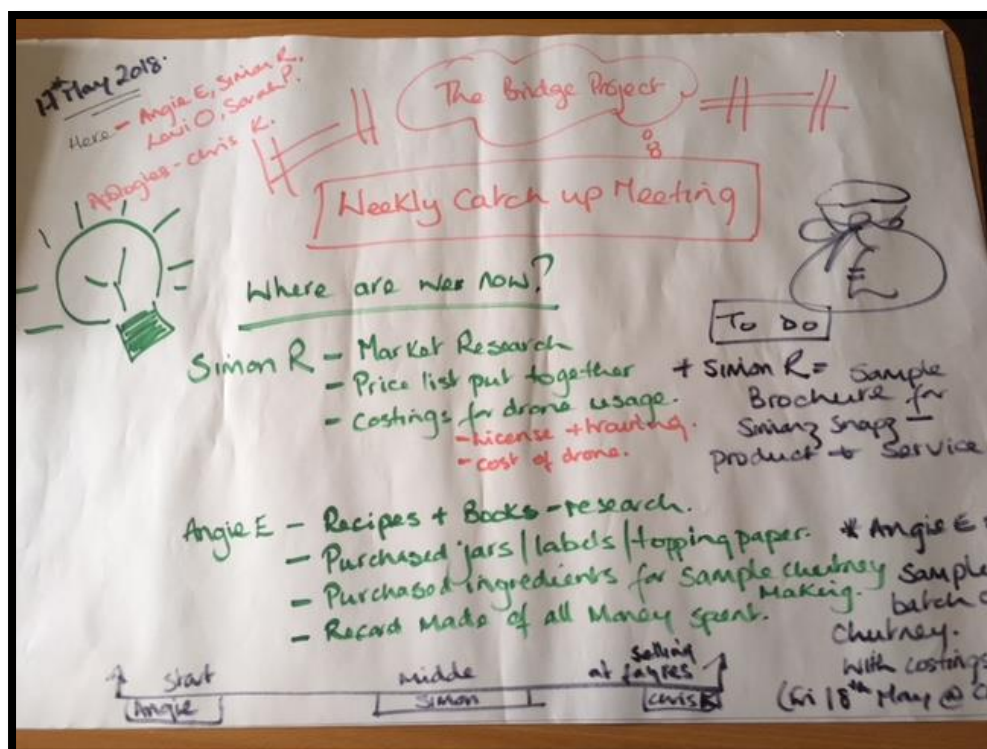
Box 3.

Personal issues
- Health and other personal circumstances. One participant has had to withdraw from the project due to serious health issues that meant continuing would have been detrimental to her health. Self-advocates often have limiting long term illnesses that will affect the speed at which they can implement decisions as they cannot sustain working seven hours a day.
- Anxiety about taking on new things or taking on risks. Most of the self-advocates have felt anxious at some time, even when they appear to be confident individuals. Anxieties include taking on responsibility, being good enough for the work or difficulties in understanding the new words involved in business. It is possible that some mask the extent of their disability to present themselves as more confident than they feel they are.
- Financial issues. Benefits, and what will happen to them when you start working are a concern. Most self-advocates in the project, when they were being paid, were not earning enough to mean that they come off working tax credit or universal credit. However, the concern that an official might decide that the payment is enough to change their situation (so they have either to come off a benefit or transfer from a benefit to universal credit), can be enough to make a person refuse payment for work. It can be easier to volunteer, doing the same work, than tackle the benefits system.
- For some self-advocates that are being paid by their charity, it can be daunting to think that a 'funded activity' will become a business. The funding that pays them can be seen as risk free. The grant or service level agreement lasts for a set time, so you don't have to constantly think about whether there is enough money to pay your wage. Changing to a business means that your wage is dependent on there being work to do, and you may lose your job at any time because the product or service isn't being bought.
- Avoiding burnout. Several self-advocates were working two or three days a week, received support paid for by direct payments on other days and had a number of days per week free. They reported that if they would burn out if they worked five days a week. For one self-advocate this was based on the experience of a job in hospitality giving her more shifts over a fortnight (within the legal maximum working hours). She experienced burnout and needed a number of days leave to recover.

Things that happen
- Practical issues, like equipment breaking or deliveries not coming. These are common to all businesses or sole traders. Self-advocates need to develop resilience and have access to funds to overcome these problems. A sole trader, who has few or no reserves cannot replace equipment easily.
- Business decisions relating to pricing or what is included in the price. One self-advocate needed to revise prices for providing a service to include costs for travel.
- Market research. One self-advocate didn't know how to go about testing the

market for her jams and chutneys. She needed help to develop a questionnaire that she could use with her friends and others. It needed to be accessible (easy read) and paper based.

- Defining the product or service. Self-employed self-advocates had questions about how to work out what to sell and how to define services that they could then price realistically.
- Refining the product based on customer feedback. One self-employed self-advocate had negative feedback when selling products at craft fairs. They had to learn about how to receive feedback and respond by altering the product being sold. They also had to deal with the frustration that other customers then wanted things the way they had been!
- Working with others. One self-advocate had needed to consider how and when to work with other self-employed people to do some jobs. This needed to be carefully worked out and include issues of equipment compatibility, personal compatibility and how to share the work.
- Keeping records. Self-advocates have learnt that they need to keep records of money received and money spent. Having a simple way of doing this (eg a receipt book or a hardback notebook) has been an important enabler.
- Having too many things going on at a time. This barrier has several aspects. Some experience overload, and need to be supported to decide what they will prioritise. Some need to learn how to say no to existing commitments to take on the work required to make the new venture work. Some need to learn how to manage relationships with people who they feel make demands on their time.

What affects employment for self-advocates

The Bridge project is trying to find out the best way to help self-advocates to get real paid work. We have looked at some of the things in society today that help or hinder this.

- Everyone with a learning disability has a right to a job - this is protected under the Equality Act (2010)

This should help, but there is a big gap between having the right and experiencing the right.

- Unemployment is very low in the UK - there should be opportunities for work, but only 6 in 100 people with a learning disability have paid work

Box 4. PESTLE Analysis of employment for people with a learning disability

PESTLE stands for Political, Economic, Social, Technological, Legal and Environmental. A pestle analysis means looking at the different factors that affect employment for people with a learning disability.

People with learning disabilities face many challenges in life. But most of us are not defined by our ability or perceived lack of it. We are not then 'fenced in', over-protected, segregated or especially cared for. This is not to say that feeling safe and having good support are not needed. What people need is the right support to participate in the wider world.

Everyone with a learning disability has the right to work - this is protected under the Equality Act (2010). But there is a big gap between having that right and having the opportunities in life that form the steps towards being ready to take on a job. This is about family life, education, how someone fits into their local community. It is also about the chances to try out jobs, and fundamentally, to make mistakes and learn from them. That is what we all do.

Many people's experience of having a learning disability will be about some form of segregation, special schools for example. But if we segregate a child through education, how can we expect them to join mainstream adult life when they have spent their formative years away from it? If our expectations of people with a learning disability are pitched low, then we design supports for people accordingly. The argument that for many people with a learning disability there is no prospect of an integrated working life is often cited as the reason; as is the cost of providing support. With the right support most people can participate in a working life, and the conditions do exist for this to happen.

What we now know

1.   In the last 30 years we have de-institutionalised the largest of our support provisions. We have emptied the big hospitals and people live in communities. We have moved away from the idea of 'asylum' in its true sense – that of a place where people are kept away, separate and 'safe'.

2.   Many people function well in their new communities. People with learning disabilities are using shops, pubs, cinemas and leisure centres, often on their own or with a supporter. It is no longer unusual to see people out and about doing the same day to day things that we do.

3.   Some people can be isolated in their own communities. Budget reductions can mean not enough individual support can be given so if someone lives with other people with a learning disability then they may have to function as a group. Fear of health and safety issues can also reduce independence (if support professionals avoid reasonable risk-taking).

4.   The vast majority of working age adults with a learning disability do not have work, further education, volunteering, self-employment or other normal 9 to 5 occupations. Research in England reports that only 5.7 percent of people with a learning disability known to their local authority have paid work (Chris Hatton, (2018) "Paid employment amongst adults with learning disabilities receiving social care in England: trends over time and geographical variation", Tizard Learning Disability Review, Vol. 23 Issue: 2, pp.117-122)

5.   Unemployment is very low in the UK - there should be opportunities for work

6.   The Equalities Act now ensures that people cannot be discriminated against due to their 'disability'.

7.   Individual payments are now available in the UK through self-directed support: direct

payments, Individual service fund, personal budgets and personal health budgets are available in various parts of the UK to help individuals design the support they want or need.

8.   There is a rise of advocacy and particularly self-advocacy to provide the missing voice from the people who themselves want a say in how their lives are spent. The rise of self-advocacy shows just how much people can do for themselves to get their voice heard.

9.   Financial advocacy is available for those people who need help in managing their own budgets and financial affairs.

The Environment we work in

The Political Environment

The places where policies are made, and laws are passed that affect people with learning disabilities getting into employment are:

- UK government: The Department of Work and Pensions is where policy about benefits (Disability Living Allowance/Personal Independence Payment, Tax Credits/Employment and Support Allowance/Universal Credit) is made. All the Bridge project areas are currently live for Universal Credit. This affects self-advocates who receive ESA because a large change in their circumstances will trigger a transfer to Universal Credit. This is a major disincentive as there have been widespread delays in payments when people have migrated to Universal Credit.
  The Equalities Act (2010) has made certain rights that were based at the European level law in the UK. Local equality bodies are responsible for supporting people to exercise their rights.
  There is help for employers of people with disabilities to provide support (Access to Work Grant), but the systems have been clumsy to operate and there doesn't seem to be much take up beyond specialist, dedicated employers of people with disabilities.
- Welsh Government or Department of Health and Social Care in London make policy about social services and health services. Policy about Direct Payments is made here. The Social Services and Wellbeing Act (Wales) came into force in 2016 and made service delivery in Wales and England different. The language of co-production has affected the way services are thought about, but it has not had a big effect in all areas yet.
- Welsh Government or Department of Education in London make policy about education and adult training. This can include support to help people get into work. In Wales there has been specific European funding to help people get into work. Carmarthenshire has benefitted from this funding.
- Welsh Government or the Department for Business Innovation and Skills make policy about supporting businesses and enabling new businesses to start. In Wales, Business Wales is the support organisation, with further support coming via Wales Coop Centre, Development Trusts Association and Social Firms Wales.
- Local Government is where social services and self-advocacy services are commissioned. It is also where adult training budgets are held for FE Colleges. Local priorities may affect the services that are available.
  Local Government also administers Housing Benefit/ Local Housing Allowance. If your income changes, they may change the amount of allowance you receive.
  Local Government Social Services Department can give you direct payments that can put you in more control of the support you receive. Different local authorities have been more or less keen to give people direct payments.

For the Bridge project, operating in both Wales and England and in three local different authority areas means that there are many different factors affecting the pilot projects.

The Economic Environment

Since 2008, there have been 'austerity' policies in place from UK government. In other words, there is less money available for public services and investment in development. However, there is more emphasis on fuller employment of the population.

A key development in disability has been the introduction of personal payments. These are delivered differently in England and Wales, but essentially, they allow for payments to be made to a person so they can make their own decisions about buying or employing support staff.

The Benefits system is a key barrier to employment for people with learning disabilities. The risk of having benefits stopped and then having to reapply because of a change in circumstances is a risk that individuals may be willing to take, but the support services are less willing to take. This sometimes leads to people avoiding even using the 'therapeutic earning' or permitted work in ESA or DLA. Another side of this is the so called 'benefits trap', the situation in which earning as much money yourself as you are receiving in benefits is very unlikely.

Employing a person with a learning disability may mean extra expense or lower productivity for an employer and hence less profit. Access to work funding can overcome some of the additional costs, but reduced ability to learn new tasks or adapt to changing circumstances will probably always reduce potential profit. However, the loyalty of employees can compensate for this, with lower recruitment costs as staff turnover is reduced.

Areas with lower than average wages in Wales have been eligible for business support paid for through European Funding. This has meant access to a business advisor or subsidised training for staff. This will stop when the UK leaves the European Union.

The relative lack of available funding for self-advocacy organisations has been a driver for People First organisations to seek to become more business-like and develop independent sources of income. However, the services that could be charged for (that self-advocacy groups can most easily provide) are dependent on a public service marketplace. Some local authorities encourage this market-based model of service provision in principle, as a way of keeping costs low. In this environment, business-like behaviour may mean that the organisation is more likely to secure funding. And in Wales, the Social Services and Wellbeing Act put a duty on local authorities to purchase from social enterprises if possible.

The Social Environment

There is a far greater visibility of people with learning disabilities, engaging in daily activities such as using leisure facilities and shopping. However, there is still a significant mismatch between the numbers of people with a learning disability wanting work and those able to access it.

There are still large degrees of patronage; of 'feeling sorry' for people rather than seeing people for themselves and their unique qualities and abilities. Where some services are now much more focussed on the social model of disability (where we consider that people can do many more things with the right support) much of society still considers people with disabilities as ill, or in need, and not able to participate in work or more complex tasks. This can affect the basic attitudes of social workers, work coaches in Job Centres, business advisors and support workers as well as family and friends.

If your parents, friends, professionals who care for you or taught you as you grew up all had and have low expectations of you, you may well have low expectations of yourself. This can be seen by others as a lack of ambition or drive, and so the person is seen to be part of the problem rather than part of the solution.

Where people with learning disabilities have well paid jobs or are part of a successful business, it is often because of attitudes picked up from parents, or because parents or carers have made things happen for the disabled person. Setting up a business that suits a disabled person's skills and motivations is something parents or siblings do, and pre-industrial age working patterns or working within the family business mean that employment is possible. This also leads to a social division between people with disabilities born into families with capital, influence or power and those born into families in poverty.

There is also a social construct of what it means to be a business person or an entrepreneur that excludes people with disabilities in general and people with a learning disability in particular. The business community in the UK is seen as being based on competition, strength, power and prestige. Disabled people rarely fit into these compartments. The mixture of being comfortable dealing with people 'like me' and the pressure to produce more for less and achieve goals makes business a strange place for many people. Indeed, to avoid the 'to be disabled is to be stupid or incapable' label (and so be more accepted in the business community), some people with physical impairments emphasise the distinction between themselves and those with a learning disability.

There are few role models for people with learning disabilities in the world of work or entrepreneurship. Richard Branson famously has dyslexia and few qualifications, but that is seen as an anomaly.

The Technological Environment

The advance of technology has revolutionised job potential for people with disabilities. Working remotely is now a lot easier and this is an increasingly used working methodology. There is greater access to communication tools that can help, such as screen readers, dictation software, predictive text and spell checking. The example of Stephen Hawking means that people do not associate using communication aids as a negative thing.

The move to doing more work in a digital environment means that work is more accessible in some ways, but this may lead to a digital divide where access to broadband determines your ability to work.

Websites are an increasingly important source of information and help, but many are not accessible to people with a learning disability. Screen readers can help, but if the language is too complex it is another barrier. The use of videos can overcome this.

The Legal environment

Employing a person with a learning disability means taking on a series of legal responsibilities that are additional to employing a person without a learning disability. The need to make reasonable adjustments and tailor the work environment to the disabled employee will take time for managers to achieve.

It is illegal to discriminate against a person on the basis of their disability, but where competence and educational achievement are commonly accepted discriminators for the purpose of job interviews, discrimination is almost inevitable. Best practice indicates that job adverts should be

accessible, but many are not.

Setting up a business or starting a new company has a legal framework that needs to be adhered to. This is relatively straightforward, but it does require advice and support that needs to be accessible to people with learning disabilities.

The Environment

There are environmental issues for all businesses and a general drive to reduce one's carbon dioxide footprint, reduce waste and reuse or recycle materials. Some of these approaches mean that businesses are thinking more holistically, and this can come with more diversity in the workforce.

Changing Identity - how we see ourselves

As self- Advocates have been developing their business ideas, they have become aware that their lives will change as they become workers or business people. Some of these changes are:

- lots of hours and effort put in
- meet new people
- getting up earlier in the morning
- find a purpose in life (a reason to get up in the morning)
- have a responsibility
- less time to volunteer
- tiredness
- stress
- making decisions and having control
- less time to socialise with friends
- won't have time to attend so many People First meetings

These can be positive; e.g. you can meet new people, helps you find a purpose in life, have more control in your life and to have a responsibility.

A lot of these changes were about lifestyle, which is one way we show our identity.

We also identified that how we view ourselves is important too. Do we see ourselves as a worker or a business person?

Those who had jobs talked about having a drive or a passion to work, that it was the only option for them (as being unemployed was too awful). They also said that it came with having responsibility for bills or paying for things that you wanted to do.

Those who were self-advocates talked about wanting to change things (through Quality Checkers), about working and volunteering for self-advocacy groups and helping others to be better self-advocates through training. One researcher didn't see himself as a self-advocate any more. He was a worker and a researcher.

When we talked about these things, we had a discussion about avoiding burnout. Burnout is when things get too much and it affects your health, physically and mentally.

Mal: *Would your life change if you became a worker? I was asking questions like 'what if your job took you 9-5 Monday, Tuesday, Wednesday, Thursday, Friday, what would that mean?'*

Kerry: *It would mean that I would have to er .. well it would mean that the council wouldn't need to give me support anymore, or it would mean I would be supporting myself, because I would be paid to work, but I'd, I'd burn myself out.*

Avoiding burnout is about keeping balance in your lifestyle. Jess (working for MLMC) had a particular story

Jess: *In that new job, you start to have those early mornings, lots of meetings and getting that understanding of what it means to be a professional, change the way you dress and that sort of thing. I started to do martial arts, so I started to do something for myself in the evening, though it took up a lot of my evenings.*

Mal: *Was that a conscious decision to balance things a bit more?*

Jess: *Yeah, so it was about personal skills, feeling comfortable and safe when you are on your own, but also, I need to finish work at this time because I am going to this martial arts class at this time. I paid for it, I am going to do it and I still feel that way, so I still go. I got a new job, new skills, slightly less of a life and a lot more stress, but I learnt more things about myself as a worker, what it meant to be a works, different responsibilities mean and where to find that balance. And I learnt a lot of resilience, but then recently I got more support in the form of my wonderful person Lisa, which has allowed me to have more of that balance. I learnt new hobbies, I've taken up new things, I've learnt how to take back a bit of my life so I'm at that point now where I have a job, and I work so that I can have my life. But I do have a lot more of a life than I used to.*

Anne, working in a business had a different story

Anne: *What works for me…. the other side of me working silly hours... is that if I want to take a 3-hour lunch break … I can. Some of it is my choice. Some of it was at the start. To run a business, you just have to suck it up and get done what needs to get done, but now it's my choice to work silly hours, so I can take some time off 9 to 5.*

For self-advocates, life is more complicated.

Kerry and Lucy worked together in an exercise and Kerry feels she is always dealing with professionals, when she is working, when she is volunteering for DPF and in her home life.

Lucy: *Me and Kerry have worked out we are quite similar. Kerry works at People First Dorset 7 and a half hours a week and volunteers as well. We both get direct payment support, so someone comes and supports us, live independently in a flat. Kerry has a job Quality Checking. We socialise with friends … and I could probably go on...*

Kerry: *But I take that home with me because my support helps me to work out those things in my life anyway. So I always take it home because I'm always speaking to a social worker or having to speak to some professional whether*

I'm at home or at work…. not speaking to professionals doesn't come into my life [because of family/home circumstances].

Kerry's personal life is 'professionalised' as she is cared for. This sometimes adds stress, so thinking about the work-life balance is more complicated. Kerry needs a balance between work/volunteering, caring for herself and "me time" or relaxation time.

For Kerry to avoid burnout she probably needs to limit her working time. This needs to be part of the plan when developing a business. But Kerry expressed a strong desire to work full-time.

Kerry: *If there was someone out there who would give me a full-time paid job, and there wasn't so much hassle with it, I'd take it… And the benefits people. If there wasn't so much hoops to jump through, then I'd take a full-time paid job.*

Changing Identity - how other people see us

We have also seen that other people or organisations see us differently as we have developed our business idea or begun trading.

We wrote down what we thought others would say about us. This is just what we think - we haven't asked them in real life. We also thought about how we would like other people or organisations to see us. These are shown in Table 1 for two sole trader businesses, one of our self-advocacy groups and for Barod, a business employing self-advocates as equal workers.

Everyone used strong, positive words to describe their business almost all the time. People probably don't want to admit to any bad views they might have heard. These words are often our own words, our jargon; words that we feel happy using about ourselves. They are often based on our values, or what we think is special about us.

There is sometimes a difference between what we think people say or would say about our business and what we would like them to say about our

business. Some of this is because we want others to see our business in a good way so they will buy our goods or services. So, we used words that we thought would make our businesses more successful.

Taking the leap from benefits to earned income

The leap from receiving benefits to earning your own money is a very big one. It is all the more complicated at the moment due to the changes in the benefits system (from Disability Living Allowance to Personal Independence Payments and from Employment and Support Allowance to Universal Credit). And this is just for a single person. If you have children or are living with a partner, then it is even more complicated.

A few scenarios were developed to illustrate the problems. They are based on real examples. Each one has a question that makes the difference between:
- being able to work or not or
- working more hours meaning getting less money.

This shows the leap of faith that is needed, because sometimes you can't get an answer about how your benefits will look until you apply. Also, sometimes things change just a little after you have the answer, but that small change affects the money you get.

Table 1. How other people see us

	How we see ourselves	How close organisations see us	How customers see us	How people who don't know us see us
Simon's Snaps				
See myself	Clever, creative, media	Independent, creative, adaptive	Creative, professional, inexpensive	Independent, insightful, quirky
Want others to see me	Unique, reliable, recognisable, knowledgeable, honest			
Soapy Waters				
See ourselves	Bespoke, arts and crafts	Family, friends	Expensive, competent	Back side of card, looking for soap
Want others to see us	Professional, make fantastic handmade cards, puts heart and soul into every card, reliable, other sellers shitting themselves			
CPF				
See ourselves	Family, empowering, innovative,	Knowledgeable, indispensable, conscientious,	Inclusive, experts, safe space,	Exciting activities, dynamic, value for money,
Want others to see us	member-led	coproduction	equality, established, experts by experience	egalitarian

	How we see ourselves	How close organisations see us	How customers see us	How people who don't know us see us
Barod				
See ourselves	Accessible, dynamic, everyone equal	Ally, innovative, experts	Professional, good at our work, reliable	Small, activists, quirky, disability/ service, are we ready?
Want others to see us	Strong/resil-ient, well paid, growing	Thinkers, pioneers/path-finders, part of the network	Make a difference in people's lives, adaptable, bespoke	Well known 'recognised brand', recommended by peers

Box 5. The leap from benefits to earned income - scenarios

Mr A lives on his own. He gets housing benefit, ESA (support group) and PIP. He currently gets £20 a week for 2 hours of work under the permitted work rules. Once the social enterprise is set up, he wants to work 12 hours a week. He needs support to work. The support will come from having a co-working arrangement (ie two people working together on the same task), rather than an individual being assisted by a job coach or support worker. The social enterprise is being set up by a self-advocacy organisation. They are not a supported employment provider.

Ms B needs support with personal care which is funded by the local authority. She lives on her own and works a few hours a week for a social enterprise under permitted work rules. The DWP have said that her permitted work can continue indefinitely. She receives ESA (WRA) and PIP. She would like to work more hours. She would need support from Access to Work if she is going to increase her hours, but she will also need more personal care. Personal care cannot be funded through Access to Work, and the local authority has reduced her personal care support budget. She would need to earn enough money to pay for personal care support while she is working. Can that work-related cost be deducted from her income when calculating her income for Universal Credit purposes?

Mr C lives with his parents. He doesn't want to work more than 15 hours a week because he doesn't want his earnings to affect his benefits (currently ESA support group with permitted work.

He also gets PIP, and hasn't realised that PIP won't be affected by his earnings or number of hours worked).

Ms D is in an adult placement/shared lives arrangement. The local authority deals with the funding for that and she isn't sure if housing benefit is involved. She does not currently work but wants to set up her own business. She probably won't make any money for the first year, and after that there will be seasonal fluctuations in her costs and her income. Some months she will have lots of costs for making the product; other months she will make a lot of income selling the product.

Mr E already works 16-24 hours a week as a freelancer. His income is fairly stable throughout the year. He works in the knowledge sector, so his costs are low. He gets housing benefit and working tax credits (including the disabled workers element). He also gets PIP. He wants to know what will happen when he is transferred to Universal Credit.

We have contacted Job Centre Plus and made contact with local partnership managers. These people are responsible for meeting intermediary organisations to help them support people in migrating to Universal Credit.

Our contact has been encouraging, and changes to Universal Credit in 2018 were positive (advance payments being one), but there still seems to be a significant difference between how the process should work and the actual lived experience of people with learning disabilities.

We have produced a jargon buster for Universal Credit, but it still seems necessary for individuals to be supported when they make a claim or migrate to Universal Credit. This is in order to make sure the policy of access to special support is upheld.

However, in the current transition between Employment and Support Allowance and Universal Credit there has been an ethical dilemma. Anne writes:
Ethically, how can we encourage people to take a course of action that means they need to claim UC before they have been migrated to it? Claiming UC before being migrated means they get no transitional protection. The system is not designed for people who want to start a business who could not get a job

on the open market – and where this is recognised because they are in the support group of ESA.

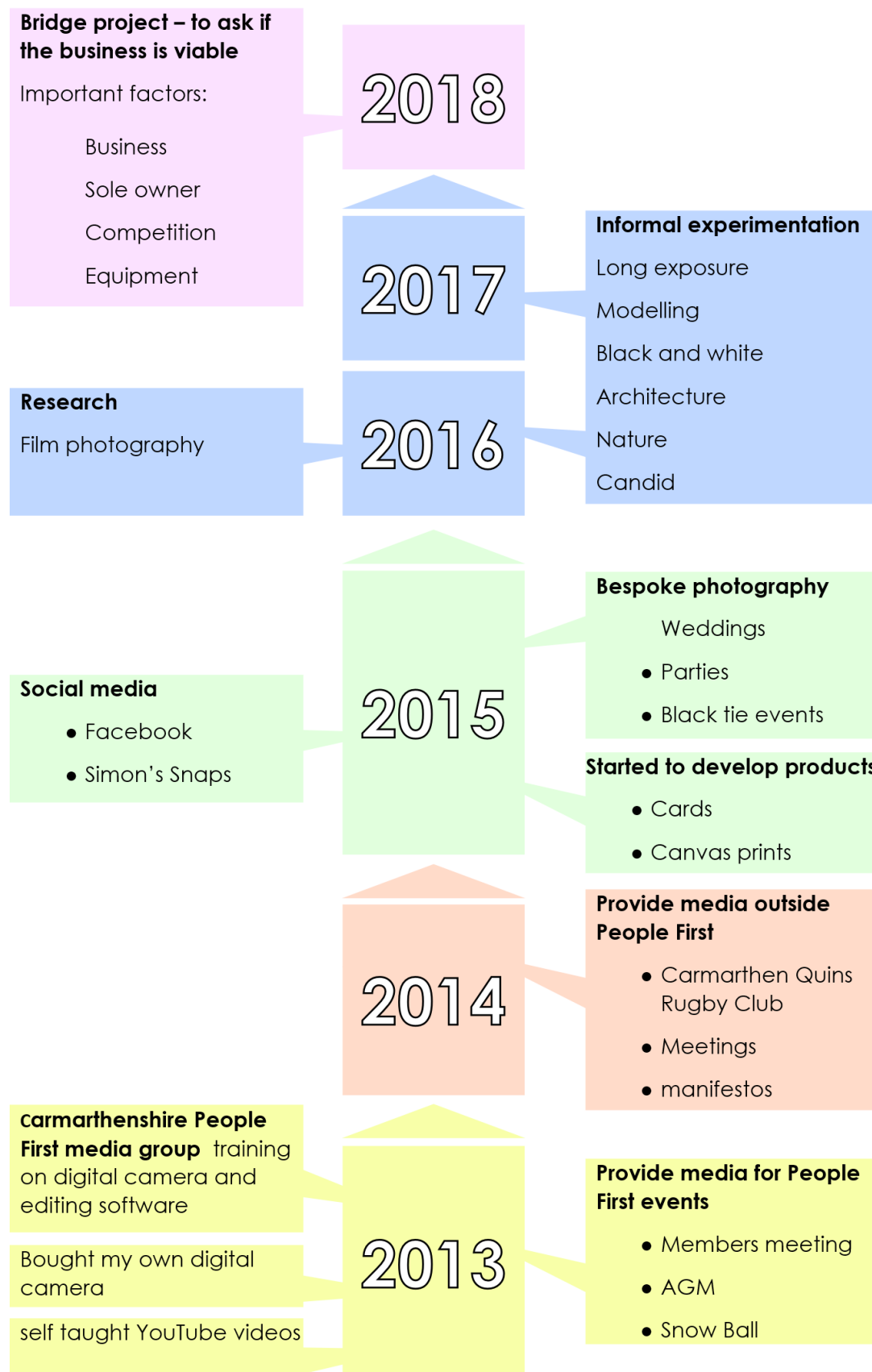## What is needed to make self-employment a realistic option?

In Carmarthenshire we have been supporting four members of the People First group who have self-employment business ideas. The three businesses were at different stages when we started and have travelled at different rates.

One business has begun trading at local craft fairs. One business is in the process of testing ideas and seeing what might be required for the business to become possible. The person developing the third business idea has had some personal challenges, including serious health issues and has withdrawn from the project for now.

Our learning so far is

- Self-employment opportunities take years to develop.
  The second business, Simon's Snaps has progressed quite a long way. The idea started six years ago with a media group in the People First group and has developed slowly (see Picture 5). It is now at the stage of thinking about taking the plunge and starting trading, registering with HMRC and becoming a real business. Developing the skills has taken a long time, and developing the self-esteem and resilience needed can take as long again.

- You need to decide whether the business is a hobby business, earning some pocket money, or a business that will provide enough income to come off benefits.
  One of the self-advocates is very active in the People First group. The time taken to make and test out products, do market research and attend training has shown her that becoming a business person will mean giving up her activities with People First. This will probably mean that she keeps the business as a hobby business.

Picture 5. Simon's Snaps timeline

Bridge project – to ask if the business is viable

Important factors:

 Business

 Sole owner

 Competition

 Equipment

2018

2017

Informal experimentation

Long exposure

Modelling

Black and white

Architecture

Nature

Candid

Research

Film photography

2016

Bespoke photography

 Weddings

- Parties

- Black tie events

Social media

- Facebook

- Simon's Snaps

2015

Started to develop products

- Cards

- Canvas prints

2014

Provide media outside People First

- Carmarthen Quins Rugby Club

- Meetings

- manifestos

Carmarthenshire People First media group training on digital camera and editing software

Bought my own digital camera

self taught YouTube videos

2013

Provide media for People First events

- Members meeting

- AGM

- Snow Ball

- Support is needed.
  All three potential business have needed individual support and encouragement over the first year of the Bridge project. It seems unlikely that they would have progressed very far at all without this support. This has led us to develop some thoughts about what support is needed and how it can be provided. What is suggested is a Maker's Cooperative that can provide two types of support:
  1) help to run and manage a business and
  2) back room services like basic bookkeeping, insurance or payroll.
  There is also the need to support people through benefit changes or with using direct payments or applying for Access to Work funding. This is shown as a diagram in Picture 6.

Picture 6. The artisan collective
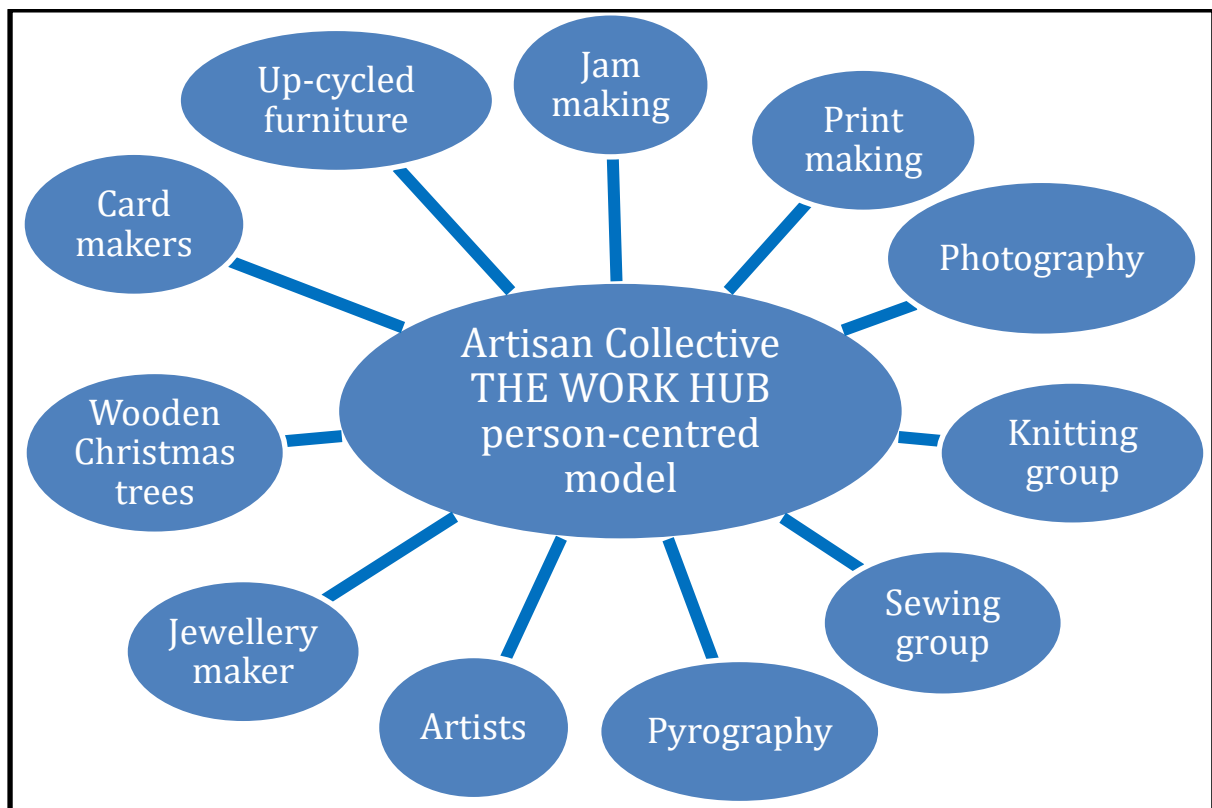
© Social Firms Wales

- Family attitudes and support are crucial.
  Anne mentioned in a reflective diary:
  Most successful self-employment is done by people whose family provide both sorts of support. You only have to look at the success stories in the media, and there is always a parent or a sibling who was involved in the setting up, management and oversight of the business. Could a collective/hub open self-employment up to people who don't have entrepreneurial family?

Interim findings: organisations

Growing a business from an existing charity

How do you go about developing a business in a self-advocacy group?

In our two pilot organisations we have followed the changes involved in turning an existing, grant funded / service level agreement funded, activity into a business.

MLMC have developed a training and empowerment strand of work called 'Power Up'. This has been funded by Oxfordshire County Council for a number of years. The funding provides a coordinator post. Other costs are covered by the fees charged to organisations using the services provided by trained self-advocates.

PFD have been receiving funding from Dorset County Council to provide a Quality Checkers service for day and residential providers in the county. The funding provides for a 16 hour per week coordinator role, a number of self-advocates as checkers plus travel and admin expenses. However, this funding will be ending and if the service is to continue it will need to be paid for by the service providers. PFD did 36 quality checks in 2017-18 so have a fairly clear idea of the time it takes to carry out a quality check and the average cost of one. However, they need to alter the format of the paperwork and think about how to present the new service in a way that makes providers want to purchase their services.

Both pilot projects have had some basic business development training and support from Barod and SFW. The following sections outline the learning so far:

Business-like thinking

It is important that groups develop business-like thinking. Table 2 lists five areas where current thinking and business thinking are different. These areas are where we have seen some change as well as some barriers to overcome.

Table 2.

Current thinking	Business thinking
A risk-averse way of thinking and decision making. Don't spend money we haven't got.	A risk-taking way of thinking and decision making. Invest in setting something up without knowing if it will pay for itself immediately,
Centralised control with slow decision making	Control put where it needs to be to make quick decisions and be flexible
We know how much the budget is for this service. As long as we don't overspend everything is alright.	We know how much it costs to deliver a unit of the service, and how much we are being paid for that unit of service.
We have to do what we put in the funding bid, even if it doesn't seem to be working well.	Being customer (ie the person who pays) orientated, so need to find customers and give them something they will pay us for.
We know how much money is coming in when and have some certainty about when we can pay bills.	Income comes in at lots of different amounts and times. We have to have some cash in reserve to pay salaries. We have to chase customers if they don't pay on time.

The changes that are needed are really a culture change for the whole organisation, not just the team leading the activity that will become the business.

Barriers and enablers

We have already talked about potholes for people trying to get real work or develop their own business. Here, we are thinking about potholes for organisations trying to develop a business**.**

They have had **legal issues** - deciding what legal structure to use to trade, checking you are able to do the new business activity. There are **marketing issues**. Both organisations have a history and a reputation that might affect which markets will work. Any business needs to describe the service it is selling and how this affects other things your organisation is doing. There are **financial issues**. Will you be able to run at a loss in some months or quarters? Do your financial systems work for a business?

There are **management** and **people issues**. Will self-advocates be given a contract? How will you cope with varying demand? What do you do if someone wants to work somewhere else as well? What if someone doesn't want to be paid? How do you coordinate your team an manage the change? How do you cope with staff changes? How can you deal with conflicting priorities? How do you manage your time?

There are also questions about the **organisation**. How does my organisation make decisions? How can we ask for a change in policy / strategy / practice?

Finally, there is **learning to develop a business**, making sure the self-advocates are fully engaged and are not just along for the ride

Some responses to these were:

Bridges - things that you can do before you meet the pothole:
- one project asked for help from the charity manager to find out how to get the charity to form a separate company to trade
- one project has a time bank or community credit system that can be used to reward those who do not want to get paid for their work
- both projects have set aside time each week to work as a group to develop the business idea

- one project has had some authority delegated to the co-ordinator so that decisions can be made more quickly
- both projects and self-advocates have received adapted, accessible business support from Barod and SFW (Picture 7).

Picture 7. The 10 business blocks showing where we are doing well (highest) and where we need to work (lowest)

Ladders - things or people that help you out of a pothole:
- both of the projects have asked for help to sort out their legal structure so they can trade beyond the aims of their charity
- one project was supported to develop a brief for a graphic designer to make promotional leaflets
- one project has had an additional staff member allocated to developing the business idea.

Leaps of faith - actions by the person to overcome a pothole:
- one project had to rewrite the service paperwork in order to make it fit for purpose for a business. This took a lot of time and had to be done before the service could be delivered, and before any work was available to pay for the time.

Some potholes have not been avoided and as yet there are no solutions:
- one project has been delayed by the organisation needing to re-tender for its core funding
- one project has the problem that staff and self-advocates are already fully committed and don't have the time to put into developing the business.

Box 6. Things that happen

- Business decisions relating to pricing or what is included in the price. One project has done a pilot first contract and is reviewing how much it cost in detail to check that they made a profit.
- Market research. One project has done extensive research into similar services provided by other self-advocacy groups and service providers to the learning disability world. Working out who is a competitor and who is a potential partner is necessary before you can work out who to approach.
- Defining the product or service. Self-employed self-advocates had questions about how to work out what to sell and how to define services that they could then decide what price to charge.
- Legal issues. The projects seeking to become businesses have had to consider their legal form.
- Payment of workers. One project has a pool of self-advocates who will help deliver the service, but some do not want to be paid. They are already linked into a local time bank or community credit system and use this system to reward those who choose to volunteer.
- Redesigning the product. When a service is provided as part of a service level agreement with the local authority then the local authority is the customer and paperwork and systems need to work for them. If the same service is provided to paying individual customers or organisations, the paperwork and way things are presented becomes more important as you are trying to impress the people you are interacting with. This redesigning can be time consuming but needs to be done before the service can be re-launched.
- Governance issues. Both projects have had to make presentations about the business idea to their board of trustees. This dialogue has stretched over several board meetings that are months apart. It takes a lot of time to prepare the case and for the self-advocates prepare themselves to present the case. Also, charity boards (with or without self-advocates) can have a steep learning curve to take on business

> concepts.
> - Management issues. Often within a charity a project is quite clearly defined and a project worker has a clear idea of the limits of their authority. Developing a business idea involves the team becoming more proactive and tests the boundaries of authority (eg decisions about what services can be offered, what the price structure is, who can negotiate, can we collaborate, taking on new workers quickly). Sorting out the boundaries beforehand can make things a lot smoother on all concerned.

How others see you

The projects are just starting to see that people and organisations see you differently when you have a business attitude. They are working on business ideas led by self-advocates, so the changes in how self-advocates see themselves, and how they project themselves to others is part of that process. It is taking longer than we thought.

The projects have a good idea of how they want other to see them. They use words like confident, reliable, professional and helpful. They are also nervous about whether they can meet others' expectations of them as individuals and as businesses.

Barod has just celebrated its sixth birthday and its experience is that clients take time to adjust from seeing workers as people with a learning disability to part of the team. Some things that affect this are:

- Who picks up the phone or answers emails?
- Who does the high-profile work, or takes the credit?
- How do workers dress?
- How do workers communicate with each other? Who takes the initiative? Who asks the questions?
- Do you always work in pairs (self-advocate plus a team member) or do you work on your own (both self-advocates and other workers)?
- Are self-advocates represented at every level of the business?
- How does supervision or worker appraisal work? Are self-advocates involved in appraising or supporting others?
- Does everyone get paid the same? Or according to their role? Or is there a staff:self-advocate divide?

Some pieces of advice for businesses trying to make this happen are:

- Be clear about the values that underpin your business, and make sure the way you work matches them
- Be prepared to make mistakes and ready to change things
- Think about what you mean by 'co-working' and 'co-production'
- Think about what it means to design a job for a person and how far you are prepared to do this for all workers (not just the self-advocates).

The end

Credits

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The report was written by Lucy Hinksman and Bryan Collis for the Bridge Project.