Learning-by-doing together: a community-university participatory research partnership to employ peer support workers (PSWs) with learning disabilities in community supported accommodation.

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Abstract

Learning by doing together is an innovative action research project that has developed an approach to co-designing jobs for people with learning disabilities in adult social care settings. CHANGE, KeyRing and CERIC worked together to design and recruit to a peer worker position in KeyRing. We created a job design method called 'community job crafting' that draws on participatory action research to co-design a job. Our job description and person specifications were co-produced and created as easy read. From our reflections on the process the research team has created three toolkits to share our learning with others.

Introduction

This project responds to an idea proposed during an event run by one of our partner organisations CHANGE to reflect on the Winterbourne view scandal which uncovered the systematic abuse of learning disabled people within a private institutional care setting (Panorama, 2011, Bubb 2014). The event, 'Our Voices, Our Choices, Our Freedom', was co-hosted with Lumos and brought 100 people with learning disabilities from 35 self-advocacy organisations together with the specific objective of exploring and campaigning for the closure of institutions (CHANGE, 2014). The event contained a mixture of activities including workshops through which groups made proposals. One of the workshops entitled 'Closing Institutions. Why is this important? How can People with Learning Disabilities get involved?' proposed that:

"People with learning disabilities MUST be properly employed to work in care settings." (CHANGE, 2014: 23).

The idea was that this may contribute to shifting the power imbalances between service providers and service users. CHANGE is an organisation that is led by disabled people and staffed on a co-worker model whereby people with a learning disability and people who are not 'so labelled' work together on the same job. The research team based at CHANGE

proposed that a peer support model might provide the flexibility to incorporate expertise by experience onto the staff within disability services. In the words of Shaun Webster, European Project Co-ordinator for CHANGE who took part in the question and answer panel at the 2014 event

"[p]eople with learning disabilities have a lot of skills to support each other" (CHANGE, 2014: 19).

The event set the agenda for this project. In our project the organisation that committed to employing learning disabled people within its service delivery team is KeyRing, a supported living provider. KeyRing operates a network model of service delivery that is designed to draw in the 'assets' of the people who use the services (members) and others in the community. An inquiry group made up of five KeyRing members (who use KeyRing services), a service manager, a co-worker research team from CHANGE and two university researchers from the University of Leeds worked together to design a 'peer worker' role to be created within the organisation.

This core inquiry group is embedded within a wider network of stakeholders. Two other partner organisations committed to learning through this process whilst a wider network of interested provider and wider sector organisations has built throughout the project and associated dissemination events and activities.

Acknowledgements

This project would not have been possible without the enthusiasm, energy and sheer will power of our inquiry group.

Terminology

Throughout this report we use the term 'people with learning disabilities' to refer to people who have been given a label of 'learning disability'. We note that some people prefer and use the term 'learning difficulties'. The people with learning disabilities at CHANGE prefer the term 'learning disability'. When CHANGE was first set up (in 1994), people with learning disabilities at CHANGE wanted to campaign for changes for all disabled people, including people with learning disabilities. They wanted to be seen as part of the 'disability' movement. This is why CHANGE prefers the term 'disability'. This terminology became adopted throughout the project. Within KeyRing people use the term member to signal their use of the service and connection with the organisation.

Background

Learning disability and employment

Even though many people with learning disabilities aspire to work (Smyth and Mcconkey, 2003; Emerson et al 2005, Jahoda et al, 2008), the labour market excludes them. The employment rate of people with a learning disability is very low indeed. During 2018-2019 a mere 5.9% of adults with learning disabilities known to local authorities in England were in paid employment (NHS Digital, 2019). In Scotland the figure was 4.1% (Scottish Commission for Learning Disability, 2019). Equivalent data is not gathered in Wales or Northern Ireland (Mencap, no date). Analysis of the English statistics demonstrates that levels of employment have fluctuated over the past decade but they remain low and have not increased over time (Hatton, 2018). Within the wider population of people with learning disabilities, who do not use specialist services (and who aren't covered by this data), levels of employment might be higher (Emerson and Hatton, 2008). However, data collection is patchy and earlier research should be treated with caution because the size of this group has expanded since eligibility criteria tightened following the introduction of austerity measures (Melling, 2015).

The data demonstrates very little progress, yet the employment of people with learning disabilities has received a great deal of policy and professional attention (for more detailed policy reviews see Blamires, 2015; Humber 2014 and Roulstone and Barnes, 2005). Since the late 1990s employment has been seen as a key element of the social inclusion of people with learning disabilities. Policy development in the area of learning disability was shaped by the ideological orientations of the Conservative and New Labour governments as well as wider developments in disability law and politics such as the introduction of the Disability Discrimination Act 1995 and the mobilisation and activism of an International Disabled People's Movement (Roulstone and Barnes 2005; Goodley 2001). As the policy landscape continued to evolve under the banner of 'austerity', opportunities for employment began to contract, nationally and in regional contexts (Hall and Mcgarrol, 2012). Moreover, further changes are likely since a policy review of adult social care is ongoing and meanwhile the Covid-19 pandemic and potential for change associated with the UK's exit from the European Union are set to transform the terrain.

People with learning disabilities use a range of state services that have distinct and differing functions (health, social care, social security) and the objective of participation in employment cuts across them (Hunter and Ridley, 2007). A central part of the policy agenda has been to coordinate action across government departments, state agencies and a growing sector of specialist private and voluntary support agencies (Humber 2014; Melling 2015). More recently however a gap has emerged between employment and social care, leading some to argue that a growing number of people with learning disabilities are finding themselves falling in between (Hall and Mcgarrol, 2012). This is because social care is increasingly confined to those in most need and, at the same time, there is a risk that the providers of employability

and supported employment programmes only select those who are 'closest to the labour market' in order to meet the requirements of their contracts (Hall and Mcgarrol, 2012; Humber 2014; Bates et al 2017). In light of austerity Blamires (2015: no pagination) asserts that

"the current situation for people with learning disabilities appears bleak, with the combination of little prospect of employment and significant cuts to welfare provision".

Where welfare provision is accessed, policy emphasises individualised approaches, draws on personal budgets and specialised employment provision underpinned by disability employment funding (Humber 2014). A central strategy in the employment agenda for people with learning disabilities has been the development and implementation of supported employment (Beyer et al 2010). Additionally, 'Access to work' provides funding for practical support to work or to start up a business but has been reportedly difficult to use by people with learning disabilities (Melling, 2015). Thus, people who independently gain employment through competitive recruitment processes can apply for support through access to work which operates alongside a statutory right on the part of employers to make reasonable adjustments (s.20 Equality Act 2010). On the employer side, the provision of information and best practice guidance along with marketing of the 'business case' for employing people with learning disabilities to employers has happened though the 'Disability confident' campaign. Policy oriented research has focussed on identifying, optimising, and evaluating employment options for people with a learning disability. It has identified and analysed ways to evaluate outcomes for individuals against measures such as quality of life, job satisfaction, motivation and health (Beyer et al 2010; Akkerman et al 2016; Kocman and Weber, 2018; Robertson et al 2019).

Thinking about learning disability and employment

A criticism of the disability employment policy is that it continues to focus on the supply rather than the demand side of labour (Barnes, 2012). The emphasis is on changing and developing prospective employees rather than changing and developing employers and workplaces. The dominant employment model of significance to people with a learning disability is supported employment (Hunter and Ridley 2004; Beyer et al 2010). The policy is associated with success in placing people with a learning disability, into employment. And in fostering positive outcomes for individuals as measured through concepts such as quality of life and health outcomes. Nevertheless, it has been criticised as underpinned by a 'normalisation goal' (Roulstone and Barnes 2005). Focussing on 'fixing' the deficiencies of workers with a learning disability rather than unsettling the way that work is thought of and organised. A social model perspective on employment diverts attention from the individual and onto wider structures and processes. It removes the 'causal link' between impairment and disability and instead considers the environments and cultures that disable people with physical, cognitive or sensory impairments (Barnes, 2012). Taking a social model approach therefore gets us thinking about: a) the way that work is organised b) the wider factors associated with exclusion from the labour market such as education, transport and culture and c) wider ideas about what work is and what it means in society (Roulstone and Barnes 2005; Barnes, 2012).

Scholars of learning disability have built on the social model approach to think about some of these wider concerns around employment (Goodley, 2001; Bates, Goodley and Runswick-Cole, 2019). A different way of thinking about impairment has informed some of this work. In the context of learning disability scholars have debated the meaning of learning disability as impairment and stressed the importance of thinking of this too as socially constructed. One of the opportunities that this way of thinking allows for is to 'reculturalise' learning disability. This means to think about how the social relations between people with learning disabilities and with their wider support, can be enabling. Goodley (2001: 221) uses this approach to shed light on the *"collective resilience"* of people with learning disabilities that *"seemingly emerge against all odds"*. Thinking this way helps to find a way through the somewhat bleak outlook identified above. In their article 'Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity' Bates, Goodley and Runswick-Cole (2017: 162) use the Goodley's concept of Dis/ability to shed light on the ways in which people with learning disabilities, their representative organisations and their supporters

"have developed many imaginative ways of resisting precarity and working austerity."

Our project chimes with this approach. Policy approaches should learn much more from people with learning disabilities, their representative organisations and their supporters. Moreover in working together to find and enable this *"distributed competence"* (Booth and Booth 1998 cited in Goodley 2001) within the social relations of people with learning disabilities and to seek to include it within organisations, the expectation is that we start to think differently about work and employment within these settings.

'Proper' employment in care settings

The demand outlined in the introduction that people with learning disabilities be 'properly employed' raises a number of points that warrant closer attention within this section.

In a context of profound under-employment, attention turns to the long-held recognition that disabled people facilitate the employment of others (Bates, Goodley and Runswick-Cole, 2019). In navigating disabling environments and using support services, people with a learning disability make work and employment for others. It is logical to see this labour market as a source of employment for people with learning disabilities. The idea is not a new one, the 2001 White Paper 'Valuing People' considered the interplay between day centres and supported employment and sought to promote the employment of people with learning disabilities in the public sector (Roulstone and Barnes 2005; Blamires, 2015). Nevertheless disability scholars reflected with caution on proceeding on these lines:

"we remain concerned about these aims to deploy people with learning difficulties, in different ways, in the existing service culture" (Roulstone and Barnes 2005: 225).

The demand of the workshop participants is not a demand that people should be *placed* in employment within these settings. The motivation behind the demand is to *change* the dynamics of relationships between the users and providers of learning disability services and to *change* the services themselves. But Roulstone and Barnes (2005) contend that employing people with learning disabilities within existing services, rather than in mainstream employment, maintains the status quo and could impede the development and resistance of people with learning disabilities. In the context of Winterbourne view, the trigger for the reflection and response of the workshop participants, violent and abusive attitudes and culture would not be addressed by simply switching from one asymmetrical power relationship (service user) to another (employee). Any approach to employing people who use learning disability services within the delivery of such services must entail and engage wider commitments to work towards cultural change and to empower rather than to appropriate the contributions of people with learning disabilities (this theme is explored further in the context of peer support in the section below).

A second concern raised by 'properly employed' links to the notion of a 'real job'. Would the tailoring of a job to the *"work abilities"* (Bates, Goodley and Runswick-Cole 2017: 172) of people with a learning disability render the position to be perceived as not a 'real job' or not proper employment? The practice of job carving in conjunction with supported employment has, for example, been criticised for not creating 'real' jobs (Wilson 2013 cited in Bates, Goodley and Runswick-Cole 2017). Moreover, stigmatised assumptions about what people can and can't do could render the potential for key skills and abilities of people with learning disabilities to be taken for granted or undervalued. As Humber (2012: no pagination) notes

"For most of their history, the work and employment of people with learning disabilities has been considered simply a way of defraying care costs or of 'occupying time'" (Humber, 2012).

In the context of care settings the value of expertise associated with being a service user is recognised (Bott, 2008). Nevertheless implicit assumptions about the value of skills and cultures of caring can have important implications for pay and working conditions within the sector as research into the feminised workforce and gendered nature of care work attests (Baines and Armstrong, 2019).

This leads to a final concern raised by the requirement of 'proper employment' which demands a closer look at the quality of 'mainstream' jobs within care settings. The conditions of austerity have created challenges in the adult social care sector that in turn shape the conditions of employment. In 2017/18 82% of workers were women, 25% of the workforce was employed on a zero hours contract and the median pay was very close to the national minimum wage (£7.89) (in 2017 the national minimum wage rate for those over 25 was £7.50 and in 2018 it was £7.83) (Skills for Care 2018). Turnover within the sector is high (in 2017/18

around 30% of workers left their post during the previous 12 months and yet 67% of leavers remained within the sector) (Skills for Care, 2018). Workers within the sector have raised concerns about the fragmentation and intensification of work (Atkinson and Crozier, 2020). Whilst ongoing litigation challenges the organisation of shifts and levels of pay (Royal Mencap Society v Tomlinson-Blake).

The assertion that people with learning disabilities should be "properly employed" within care settings leads to a consideration of the wider environment within the sector and of the importance of finding ways to confront and resist some of the norms and practices that could serve to disable people with a learning disability through the creation of employment. Building on the social model of disability these considerations shift our attention to the wider organisation and delivery of care services and, drawing on Goodley (2001) and Bates, Goodley and Runswick-Cole (2017) to uncover and support the resistant possibilities of the collective social relations of people with learning disabilities to address them. The following section considers these themes more closely in the context of paid peer support employment.

Peer support

As noted above expertise by experience has been identified as a valued knowledge within care settings. The skill of offering and using peer support is a keyway to put experiential knowledge to use (Walsh et al 2018). The practice of peer support has played an important part in the instigation of change by disabled people (Bott, 2008). A growing evidence base concerning the use of peer support has led health and social care commissioners to recognise the potential benefits (Nesta, 2015). Whilst much peer support is delivered on a voluntary basis, the role of paid peer workers is also significant and peer support in some contexts is increasingly professionalised and managed as an employment relationship (Ahluwalia, 2018).

Fewer studies focus specifically on peer support within learning disability communities and, as noted by Bott (2008), the term 'peer support' is used less frequently in this context. Within a commentary on 'supporting independence' co-written by people with a learning disability and people not so labelled; the authors note that support works well when people's expertise is recognised and valued.

"It is important that people with different abilities and backgrounds learn from each other. People need to recognise our expertise. People with learning difficulties have a lot of experience – both life and work experience. Peer support (people helping each other) and being able to just talk things over with friends is really important." (Chapman et al, 2013: 196).

Keyes and Brandon (2011) identify 'mutual support' as a model of peer support. They eschew assumptions that people with learning disabilities lack insight into interpersonal interaction and pin-point a *"unique quality to peer relationships"* (Keyes and Brandon 2011: 227) through which people with learning disabilities support each other. This, they assert has emancipatory potential. The analysis uses qualitative data to demonstrate how people with learning disabilities provide empathic insight and sensitive communication to respond to the needs of

others. The study also drew parallels with research into the self-advocacy movement (citing Goodley 1997 and 1998). Peer support can encourage people with learning disabilities to be interdependent and support each other without non-disabled people intervening. Although Keyes and Brandon (2011) also identified a layering of support through which non-disabled allies enabled people with learning disabilities to support one another. Bott's review of peer support provided examples of peer support in a range of settings and included some examples of peer support amongst people with learning disabilities including within our partner organisation CHANGE. The review detailed peer support amongst people with learning disabilities through organisations engaged in self-advocacy, parenting, supporting choice and control over support needs, black and minority ethnic communities. The review found

Peer supporters with learning disabilities have been found to play a valuable albeit marginalised role in the implementation of policy developments within adult social care, such as direct payments (Bewley and McCulloch, 2004). In this context people with learning disabilities were found to be better able to provide information in more appropriate ways than others and were more likely to 'inspire' people with learning disabilities to take up direct payments. Nevertheless, the benefits of effective peer support were lost when wider systems were not prepared to then distribute the payments to people with learning disabilities, highlighting the importance of the wider system acknowledging and championing the emancipatory potential of peer support. The report's authors also highlighted obstacles to the award of contracts to people with learning disabilities in order for them to provide a peer support service. Later Bott (2008) conducted a review of peer support activity in the context of self-directed support and the personalisation of adult social care and further asserted the role of peer support.

As already noted, peer support takes place in a wide range of settings and serves a host of different purposes. Indeed one of the benefits of peer support is that it is flexible (Castellano 2012, Jacobson, Trojanowski, and Dewa 2012). It has become particularly widely used in mental health settings (Repper and Carter 2011; Welsh et al 2018) where peer support follows "recovery principles" (Cabral et al 2014). Approaches from this practice disabilities do not transfer directly since a recovery model is not relevant to experiences of learning disability. Nevertheless, research into the roles of paid or professional workers within the mental health context could help to pre-empt practical issues in the employment of peer workers. Repper & Carter (2010) identified that employment as a peer support worker provides individual benefits for the worker including self-esteem, and confidence. However of key concern to the employment of people with learning disabilities in the context of care services is Berry et al's (2011) finding of peer workers being 'othered' by non-peer worker staff. This suggests that effort is needed to ensure that peer workers are better integrated into the wider service. Another insight from mental health suggests that the dynamic of mutuality that has been found to be beneficial in the context of learning disability, can be impeded by paying one party to the peer support relationship. In this project with its emphasis on creating a paid

position it is useful to note that power sharing efforts are likely to be impacted by the employment of the peer worker (Welsh et al 2018).

Approaching job design

One common approach to adapting workplaces to the needs and abilities of a learningdisabled person is to conduct 'job carving' (Beyer and Beyer, 2017). At the heart of this process is the redistribution of existing duties (Nietupski and Hamre-Nietupski, 2000). The process typically takes the lower skilled elements of other jobs to create a new role for a person with learning disabilities (Beyer and Beyer, 2017). The approach to redistribution can differ. Three broad approaches have been identified in the literature: "cut and paste" (taking duties from a current position and assigning them to a new one), "fission" (dividing the duties of a single job between two or more others) and "fusion" (reassigning similar functions from multiple existing job roles to create a new role) (DiLeo, 1993 cited in Nietupski and Hamre-Nietupski, 2000). As already noted this practice, in conjunction with supported employment has been criticised as not creating 'real' jobs (Wilson 2013 cited in Bates, Goodley and Runswick-Cole 2017) and yet is a key source of employment (Bates, Goodley and Runswick-Cole 2017). Proponents of the process note the potential to

"combin[e] the human service competencies of tailoring jobs to consumer capabilities, interests, and support needs with the sales and marketing principles needed to partner with employers" (Nietupski and Hamre-Nietupski, 2000: 118).

Job carving goes further than the basic legal requirement of 'reasonable adjustments' (s.20 Equality Act 2010) since it entails the creation of new positions rather than the adaptation of a pre-existing one. Moreover it need not be an entirely individualised process (Nietupski and Hamre-Nietupski, 2000). Nevertheless, the route to efficiency and productivity seems to leave underpinning organisational norms intact.

The approach to job design explored here is intentionally transformative and takes as its starting point the potentiality of people with learning disabilities. It is apt to adopt this approach within the services used by people with learning disabilities since in this domain, their experiential knowledge is directly applicable and particularly valuable. Whilst this approach could equally be criticised for creating a job that could be viewed as not a 'real' job, its starting point is the "work abilities" of learning disabled people (Bates, Goodley and Runswick-Cole 2017). The process is anticipatory and collective in its approach and is designed to disrupt the taken for granted assumptions that underpin service delivery within the sector. Like job carving the practice is proactive, starts at the job design stage and thus it goes further than reasonable adjustment. Unlike job carving the practice developed here is alert to the relational dynamics of job design.

Methodology

This project is a community-university participatory research partnership which adopts the core methodological principles set out in the Co-inquiry tool kit produced by Beacon NE Co-

inquiry Action Research (CAR) (Beacon North East, 2011). The research design draws from methods in action research, participatory research and co-inquiry.

We asked the following questions

- How can we make it possible to employ people with learning disabilities as Peer Support Workers in learning disability services?
- How can being a peer support worker or being supported by a peer support worker best enhance independent living?
- How can employing peer support workers improve organisations/services?

Co-operation

Cooperation was implemented at two main levels within the team ('inquiry group').

- Within the research team (CHANGE and The Centre for Employment Relations Innovation and Change, Leeds University Business School). Cooperation to run the project happened through the research team which encompassed a person with a learning disability and a co-worker who is not so labelled working alongside a university researcher, sometimes with input from a team of volunteers who have learning disabilities.
- The actions of designing and recruiting to the post were carried out as a collaboration between the research team and Keyring. A regional manager and team of members who use KeyRing's services were actively involved in the inquiry group throughout the study. Input was also provided by support workers and the HR manager.

Co-production through workshopping

The job description, person specification and recruitment strategy generated through this project were co-produced. This meant that all of the members of the inquiry group worked together to design the job and recruit to the position. Then following further analysis of the process and the data generated through it, the research team developed tool kits.

The inquiry group worked together to generate knowledge through overlapping cycles of the steps below (drawing on Reason, 1996).

Step 1: diagnosis and planning workshop

Seven workshop brought the key actors the partner organisations (managers, current support workers and service users) together with the research team. We worked together to think about and plan a new 'peer worker' post within KeyRing. Through these workshops we drew on a range of methods including theatre, play, craft and storytelling to explore and construct different ways of knowing. Each workshop lasted a day and, aware that knowledge production is supported by disability culture rules (Currans et al 2015) we sought to work together to define and hold our research space.

Step 2: Action

We effected the recruitment and selection of a peer worker within KeyRing.

Step 2a: New encounters

And this in turn lead to new encounters and experiences (perhaps raising unanticipated issues). This experiential knowledge generated important insights that we hope are captured through our tool kits to share with other organisations.

Step 2b: Recording and sharing experiences

We planned that the inquiry group would keep diaries of their experiences (these may be oral (audio or video) or written and may make use of images or drama) to encourage reflection and learning but engagement with this was patchy so we built a time for reflection on experiences into our workshop ritual.

Step 3 Reflection

The research team conducted interviews with members of the inquiry group to discuss experiences and reflection but in practice the interactions through the workshops and the research team met between workshops to reflect and to plan on the next.

Step 4 Evaluation and translation.

The research team will collated their findings to a) distil key lessons, b) translate the lessons for a wider audience and c) contribute to a 'rolling' evaluation of the project within the inquiry group. This process worked very well in production of the job description and person specification (see Appendix 1) whilst the tool kits were written by the research team by drawing on data generated though the action research process and linking back to the academic literature.

Findings

How can we make it possible to employ people with learning disabilities as Peer Workers in learning disability services?

Within our first toolkit we outline a method called 'community job crafting'. The job crafting approach draws on the theory of job design and job quality (Shantz, 2018) and seeks take as its starting point the potentiality of people with a learning disability as situated in wider social relations. Nevertheless the practicalities of making space and implementing these processes are a challenge in times when budgets, time and energy are stretched. The success of our process was contingent on key organisational players and their will and energy. This raises the

issue of the wider context of commissioning and delivering services. If practices such as the ones described here are to be taken up more broadly time energy and resourcing must be made available within the sector.

How can being a peer support worker or being supported by a peer support worker best enhance independent living?

Our exploration and reflection of the role of peer support within learning disability services revealed that a wealth of experiential knowledge is held and used through peer support. Our job description, based on the 'six keys' of peer support developed though our workshops offer an example of how peer support can be used within the context of a particular service organisation. Our reflection of peer support as a paid job highlighted the importance of maintaining the distinctiveness of the role and of steps to prevent the peer worker from being drawn into gap filling where services are stretched.

How can employing peer support workers improve organisations/services?

The process of designing and creating the peer worker post generated energy and enthusiasm within KeyRing that fed into wider strategies around employment. The early findings of the study fed into the development of a second Community Organising role that drew on our methods of job design and 'six keys' of peer support. However it is too early to tell whether and how the practice of the peer worker shifted power relations or changed services within KeyRing. More work needs to be done to assess this from the member perspective.

Tool kit 1: Community job crafting our method for inclusive job design

How we thought about job design

When organisations think about employing people with learning disabilities they often think about how they might need to change their recruitment and selection practices.

But the first step is to design a job that fits well and brings out the best in people (an inclusive job).

Jobs are not just a collection of tasks, they are shaped by ideas about who workers are, how work is done and what is valuable.

Because very few people with learning disabilities have paid jobs, their skills and strengths are not always seen by employers and the jobs within organisations do not fit well.

Organisations that employ people with learning disabilities have found ways to adapt existing jobs so that they fit a bit better. For example by making reasonable adjustments, through job carving processes or through supported employment.

The focus of this kind of process tends to be on tasks and on support needs which is only part of what a job is and who workers with learning disabilities are.

Designing a new kind of job completely from the beginning makes space to think differently about what people with learning disabilities have to offer as workers and how that can be used and valued within organisations.

Designing a new kind of job completely from the beginning can start to change some of the usual ideas about who workers are, how work is done and what is valuable.

Through this project we worked on a way of designing jobs that we have called 'Community job crafting'.

Community job crafting offers a way to work together to find the things that people with learning disabilities have to offer and to make space for them within organisations.

We think that Community job crafting offers a way to create new spaces for people with learning disabilities within service provider organisations.

Community job crafting and learning disability services

We think that the process of designing a job with service users creates an opportunity to think differently about service users and about services.

Winterbourne View and Whorlton Hall remind us that people with learning disabilities experience abusive practices in environments such as Assessment and Treatment Units and in other contexts.

Employing people with learning disabilities within services used by people with learning disabilities has been proposed by disabled people as a way to address some of the power differences.

Employment on its own will not resolve power imbalances because employment relationships are also unequal power relationships.

We should be realistic about what job design can achieve on its own.

It is important to create inclusive employment which means changing wider ways of thinking and doing things within organisations.

The adult social care sector is facing problems around the funding, staffing and delivery of services.

Job crafting isn't a simple solution to all of those problems. But it is a step forward that service providers could try and that commissioners could support.

What is job crafting?

Job crafting is a term that is used in academic literature to talk about the way workers change parts of their jobs.

Job crafting describes people making changes to their tasks that also change what work means them and how it makes them feel about themselves.

Job crafting makes us think of doing crafts like jewellery making.

The materials of jewellery making are things like: beads, clasps and thread.

The materials of job crafting are: tasks, the way we think about the work and work relationships.

The people who made the idea of job crafting said that changing these things changes the job and the social environment a person works in.

This means that when an individual changes their own job there is an impact in an organisation.

The effect of job crafting is different depending on where and when it happens.

Sometimes it is seen as a good thing and sometimes it is seen as a bad thing.

Job crafting is a useful idea for thinking about how jobs can suit people and can change things within service provider organisations.

How we use the idea of job crafting

We designed a job together using the tools of action research and inclusive research.

After we had designed the job we looked back at what we had done and made a new term 'Community job crafting' to describe our process.

Job crafting is usually about workers changing parts of their own job but we use it to describe the way that service users made a new job for a worker in an organisation.

Job crafting is usually done by one person but we added the word 'community' because we were a group of different people who worked together to design the job.

What is good about the idea of job crafting?

Job crafting is a 'do it yourself' process. It comes from people on the ground rather than at the top of organisations.

Crafting is creative. It is about trying things out and having fun.

Crafting is about working with what you already have. It is achievable.

Within our inquiry group some people enjoyed expressing themselves through making things. Crafts were part of their creativity and could lead to business ideas.

What is bad about the idea of job crafting?

It is important that people with learning disabilities are respected and not treated like a child.

The word 'crafting' could be seen as too informal and not taken seriously. It is important that the outcome is a 'proper job'.

Not everybody likes crafts and not everybody feels creative so for some people the word craft might put them off.

Job crafting could be confused with other practices like job carving so it is important to make the differences clear.

Some people in our inquiry group felt that crafts limited the potential of people with learning disabilities. One person told a story of "people sitting in a day centre knitting" rather than going to college.

Being clear about community job crafting

Community job crafting is a process that is taken seriously by the organisation which has committed to funding and resourcing the new job.

Community job crafting brings people together to design a job that uses the things that people with learning disabilities can do within an organisation.

The process of job crafting uses lots of different activities and games to share what we know about people with learning disabilities and our organisation.

The process finds playful and creative ways to think about some very serious issues.

What is the process of Community job crafting?

Community job crafting is not just about asking people with learning disabilities what they think, it is a process of collaboration to think and work together to make the job.

The sections below share what we learned about what makes the process work well. They are aimed at the different kinds of people involved. The quotes come from our reflections on our workshops.

Service users

"I know the barriers that people with learning disabilities face"

- Your experiences are really important and give you knowledge that other people don't have.
- If you can commit some of your time and energy, get involved and give it a try.
- Expect to share your experiences.
- Only share as much as you feel comfortable to share.
- Expect to listen to other people's stories.

- Let people know if the process isn't working very well for you.
- Expect to meet new people and be part of interesting conversations.
- Expect to find ways to make decisions with others and to contribute to making a new job.

Organisations: Give the process strategic importance and resources

"Really think about what we can offer"

- Commit to funding and resourcing a new kind of post.
- Involve people who want to make this happen.
- Commit time to the process of job crafting.
- Be open to creating full-time employment or flexible work arrangements.
- Think about how the new post fits within your organisation.
- Be ready to work on the integration and effectiveness of the new post.
- Be open to what the job crafting process can tell you about your organisation.

Organisations: think about the location

- We worked with a large, national organisation but the work that we did was closely linked to one place.
- The fact that it was really local seemed to work well because we could think about how the job would work in a place and with people that everyone knew.
- The people in the location were excited about the idea and keen to make it happen.

Everyone: Form a group

"we all had fun, we all joined in...all our different ideas"

- We created a group called 'the inquiry group' which was made up of service users, a regional manager, support workers (sometimes) and a research team made up of researchers from CHANGE and Leeds University Business School.
- Think about the criteria for joining the group and advertising the group.
- The process creates a job that some of the members might want to apply for so access to this group should be fair.
- Create accessible invitations such as easy read documents or a video to explain the project so that people who were interested can find out.
- Make sure that support workers have the right information so that they can share it with service users.

Everyone: Find inclusive ways to talk and think together

"I feel right in the middle of it"

• When we met we used a workshop format.

- The research team designed the workshop activities. We were a team of people including people with learning disabilities.
- The design of each workshop responded to what we said and did in the last workshop.
- We made space for everyone to share their stories and to listen to each other.
- We thought about power in our inquiry group and in our workshops.
- We shared our access needs and took each other's needs seriously.
- We used activities and games to explore big ideas.
- We found ways to make decisions together.
- Our workshops worked best when they were fun.

Everyone: Be ready to value and use different types of knowledge

"stuff you can learn from a book compared to what you can learn from experience"

- Our way of working uses action research.
- This type of research tries to find things out by doing something.
- Some action researchers try to use different ways of knowing things:
- 1. Having experiences,
- 2. Noticing feelings and emotions and sharing them in arty ways like through drawing, music, drama, sculpture,
- 3. Making ideas that we can talk about and write about,
- 4. Being able to do something practical.
- We used different ways of knowing to make a job description, person specification, to design our way of finding and choosing the worker and to think about how the worker will work well in the organisation.
- Within the other parts of this tool kit we share how we used the different types of knowledge to make our peer worker job description and to recruit and select our worker.

Everyone: Work together in cycles of thinking, planning, doing and more thinking "Things are getting moving"

- The research team had some loose plans about the things we could think about in our workshops (like peer support and recruitment). But each workshop was designed to respond to the last one.
- We used our workshops to 'set the agenda' for what should happen next.
- Most of the action happened outside of the workshops.
- It was important to keep some time to think about what we had been doing. We had planned to keep diaries of the action but this was difficult for people to do because everyone was so busy. If we were to do this again we would try to find a different way to do this.

The outline of our workshops

The focus of the workshops would be different in different organisations because the inquiry group should decide what to think about and do.

Here is a list of the main things that we covered in our seven workshops.

- 1. Forming our group and thinking about what we can all contribute to the process.
- 2. Thinking about what peer support is, how it is done already and how to use a job to use the knowledge and skills of people with learning disabilities within the organisation.
- 3. Thinking about how we will find and choose our worker.
- 4. Building our job description and starting to think about how we will find, keep and grow the worker and how they will move up in their career.
- 5. Mapping the organisation and thinking about the different working relationships that will be part of the job.
- 6. Thinking about how we will keep and grow the worker as well as supporting them to move up in their career.
- 7. We thought about what we had learned from our previous workshops and we looked at some of the things we have made (for example job description and job advert) to decide what we think of them.

What have we achieved?

- 1. The process of community job crafting created a new post that drew on the things that we found that people with learning disabilities could bring to the organisation and responded to the needs of the organisation.
- 2. Our co-produced job description and person specification are available in easy read.
- 3. Our recruitment information day brought applicants together to find out about the job and to think about how to shine.
- 4. Our selection day used a range of techniques (such as drama and story-telling) so that people could show how they met the person specification and would make the role their own.
- 5. We don't think that everything we did was perfect but we have tried to do things differently and have learned a lot through the process.

Toolkit 2: Our approach to peer support

What is peer support?

Peer support happens when people with shared experiences come together to support each other in an equal way.

Why peer support in this project?

The "'Our Voices, Our Choices, Our Freedom' event run by CHANGE (2014) brought 100 learning disabled people together to talk about the abuse of power that happened in Winterbourne View (Panorama, 2011)

A key message that came from this event was "People with learning disabilities MUST be properly employed to work in care settings." (CHANGE, 2014: 23).

CHANGE thought employing learning disabled people as peer workers could be empowering in two ways:

- 1. Peer Support can shake up the power between service providers and service users
- 2. Peer Support can address the employment gap for learning disabled people.

Peer support is a useful way to respond to these ideas because:

- 1. It involves service users in the delivery of services this is already happening in mental health services.
- 2. It is a happening more and more in learning disability services but there is still more to know.
- 3. It is flexible. There are lots of different ways to do peer work which means it can look different in different services.
- 4. It builds on what people are doing already as peer support often happens informally in communities of people.

Peer support and power

Shaking up the power in support services can empower learning disabled people by giving them more control and influence in services they use.

There are several ways that Peer Support can shake up power in services for learning disabled people.

1. Peer Support is "a two way thing" (ws2)

Peer support is mutual. This means no-one is in charge of a peer relationship. Instead both people give something and get something from the relationship

2. "I know about living with a learning disability and the barriers that come with that" (ws1)

Peer support workers are regarded as "experts by lived experience" (Walsh et al 2018: 580).

This means that the knowledge they have gained from living their lives is valuable because it is different from the "professional expertise" provided by non-peer staff. (Beresford and Russo 2016)

3. Non-directive support: "It would be bad if they were bossy and telling you what to do" (ws5)

The Peer support is not a "top-down" practice. This means everyone involved thinks carefully about how the power is being shared.

Peer Support is non-directive. This means that no one tells anyone what to do and that the people involved support one another to make their own choices.

Peer support and employment gap

Learning disabled people are underrepresented in the job market, the employment rate is very low and has not really increased in the past decade.

There are several ways that Peer Support can address the employment gap for learning disabled people.

- "Give us a chance to work" (ws6)
 Peer support offers an "employment pathway" for learning disabled people by valuing lived experience over formal education or professional qualifications.
- 2. "Some people turn their nose up at you, they think oh we don't want him working here" (ws6)
- 3. Employing learning disabled peer support workers challenges stigma and the view that learning disabled people can't work or don't want to work.
- We learn something from every experience" (ws2)
 Employing learning disabled peer workers can equip them with them transferrable skills, work experience and professional development that can help them get jobs in the future.
- 5. "I applied for lots of jobs but as soon as they found out I got a disability I didn't get the interview" (ws2).

Peer support offers an opportunity to re-design jobs around the strengths of learning disabled people.

6. In peer support a learning disabled person is the 'ideal worker' for the role.

How did we do it?

1. "Start with what we can do" (WS1)

We used our community job crafting method to design a peer worker job that was built from the strengths of learning disabled people. We focused on expertise and experiences.

Expertise: We spent time thinking about what we were each experts in. This ranged from being a bus buddy, to being a board member, to caring for others etc.

Experiences: We used images from magazines to start conversations about our own experiences of peer support. This ranged from formal employment to informal peer support that happens in communities, friendships and families.

2. "Don't make assumptions about what people can and can't do" (ws2)

We explored some complicated and conceptual ideas about peer support.

We used drama to help us think with our bodies and our actions.

We made "body sculptures" to think about peer support in a symbolic / abstract way (Boal 1992)

We created a sculpture of a group of people standing in a circle, holding hands, leaning back, with their eyes closed and heads turned up to the sky.

We discussed the image as a group. We thought about what it looked like and how it felt to be in it.

This image was very powerful. It helped us to think about peer support as relationship and about what this relationship can offer to the people involved.

3. Deciding together:

We made a note of all the key words that came up during the body-sculpture workshop.

We discussed what each word could mean in the context of peer support.

We played a "higher or lower" game to rank the words in order of importance.

4. Six keys to peer support

From this activity we found out that there were 6 words that were important to Peer Support.

We called these words the "6 Keys to peer support". The Six Keys are all connected by Shared Experiences.

The 6 keys to peer support are:

- 1. Trust,
- 2. Safe,
- 3. Friendly,
- 4. Helping each other,
- 5. Honesty,
- 6. Time.

The Six Keys can help the peer worker navigate the process of building peer relationships as part of a paid job.

5. "How might it look on the ground?" (ws5)

We used the 6 keys to help us think about how Peer support might work in practice.

We used Forum Theatre (Boal 1992) to help us role-play problems, think of solutions and to think about how the role might work in the context of KeyRing.

- We thought about:
- Where it might fit in the organisation (ws5)
- How the role might meet both the "strategic and everyday" needs (ws5)
- If the peer work should be "proactive or reactive" (ws5)
- What support the peer worker might need (ws6)

What did we find?

1. "The relationship and dynamic might be more important that the practical tasks a support worker might do" (ws2)

We found that building good quality relationships is more important that getting formal tasks done. This is why we found it useful to drop the word support from the job title.

2. "The little emotional things that might get missed" (ws6)

We found that the peer worker should focus on the emotional aspects of support and that by doing this the service would be strengthened

3. "Its own distinct role" (ws5)

We found that the peer worker role is different from the existing roles in KeyRing. The peer worker mustn't end up gap filling, it must be a completely new role.

4. "It needs to be flexible" (ws2):

Different people do things in different ways so we needed our job description and person specification to open so the peer worker can develop their own peer support practice over time.

5. "Peer work is emotional work"

Peer support is skilled work because it involves working with feelings. The peer worker might have to do work that involves managing different feelings happening all at once.

What does peer support offer in a learning disability context?

Peer support is well established in a mental health context where is it used to support people through their recovery journey.

In a learning disability context the emphasis on journeys can be changed to meet another identified need. For example, in our project the focus was on Peer work for employment.

How does being paid affect peer work?

Being paid can create some tensions in peer support. These tensions need to be carefully managed.

Peer support is a mutual space– literature suggests that this level space is changed when one person is paid and another person is not.

When one person is being paid to share their experiences the authenticity of their intentions might be called into question.

Peer support tries to move away from professional expertise to genuine, lived experience experts. However, paying lived experience peer workers professionalises their practice.

How could it be done differently?

1. The 6 keys are specific to our project inquiry group and their experience of KeyRing. Another group of people in another setting may find different words to have more importance for their purposes

2. In our project we used the term "peer worker" rather than "peer support worker" to avoid conflation of the role with support work. The different models of peer support mean that there is some variation in the title given to paid Peer Support workers including; "Peer Support workers" (PSWs), "Mutual supporters", "Peer Support Specialists" or (PSS) and "Lived Experience Practitioners" (LEPs), "Peer Mentors", and "Buddies"

3. Our peer worker role has an emphasis on supporting keyring members through their employment journey. In other services this emphasis may change depending on a different need that has been identified.

4. Defining what "Peer" means and who counts as a Peer is a really important aspect of the person spec

Toolkit 3: Recruitment and selection

What is recruitment and selection?

Recruitment is the process of finding the people who might want to apply for the job.

Selection is the process of choosing the person who will do the job.

We thought about the recruitment process as working two ways

- 1. The person looking for the job finding out about the role and the organisation
- 2. The organisation finding out about the person looking for a job.

Why is it important to think about recruitment and selection on this project?

The decisions that we take about recruitment and selection shape who gets to apply for the job and who is given the job.

If the processes aren't open and fair people could be discriminated against.

If people don't feel like the process is fair it might impact on their feelings about applying for other jobs in the future.

If people don't feel like the process is fair it might impact on their feelings about KeyRing

Try to make decisions together

We had some difficult decisions to make and didn't always agree.

- Should the job only be for keyring members or should we advertise more broadly?
- Should the job only be open to someone with a learning disability?
- What do we mean by learning disability?
- Where should the job be advertised?

We used some weighing scales to:

- a) help us to visualise balancing the different objectives
- b) as a way to vote (by adding weights)

Think about the barriers to employment

The recruitment processes might create barriers.

"Why are you turning me down without giving me a chance?"

"People have bias or prejudice" (ws3)

Individual attitude towards work and past experiences of work can shape how people feel about applying for jobs.

"People are getting thrown into work when they haven't ever had it on their radar" (ws5) -

"They might now know what their skills are" (ws5)

Barriers could be linked to the attitude of wider support networks. Overprotective cultures or a lack of ambition of members of a support network might deter people from applying

"Family might say you can't work"

People might need support to complete application processes.

"Help to fill out the forms" (ws4)

What support is available for people with learning disabilities people seeking employment?

Support for employment – but not very good for disabled people (ws5)

Support for job seeking depends on areas

Think about how to attract applications for the job

We shared stories of job searching to think about the different ways people find out about the jobs.

"Work experience turned into a job" (ws3)

"Went round asking for a job – chip shop –card shop" (ws3)

"Looked in paper" (ws3)

"Job centre" (ws3)

"Day centre" (ws3)

"Previous manager moved to a new organisation and phoned them up to tell them about this job" (ws3)

Plan how you will select

Most people in our group felt that interviews are not helpful for people with learning disabilities.

"Interviews are not accessible"

People talked about feeling nervous about interviews and tests.

"Interviews are scary: people feel nervous"

"Try to make it informal"

"Doing a trial" (ws3)

Provide feedback and support for people who aren't selected.

We talked about the importance of providing constructive feedback.

"You might not get the job" (ws3)

"Get your hopes up" (ws 3)

What did we do?

We created an easy read job advert and advertised via the website and through local networks.

Created a short easy read application form.

Gathered information about access needs.

Ran an information day about the job

- Provided information about the job (easy read job description and person specification)
- Practiced activities like our selection day activities
- Met people who were interested in applying

• Supported people with the forms

Designed a selection day

- Since members of the inquiry group applied for the job we worked with CHANGE volunteers who are people with learning disabilities to design activities.
- Used different types of activities and linked them to the person specification.
- Invited people with learning disabilities who were KeyRing members to take part in the decision making process.
- Linked our activities to the person specification but also tried to be open to surprises.

During the selection day

- Talked about how to have a good and comfortable day.
- Carefully planned and scripted the session.
- Adapted to unexpected changes on the day.
- Kept the atmosphere friendly.

What might we do differently?

- Better plan the timing around public transport.
- Unfortunately the KeyRing members we invited to take part in the decision making didn't arrive on the day. Involve panel members earlier and make sure everyone understands the plan.
- We followed the call to "start with what we can do" and looked carefully for ways in which each person could perform well in the role the drawback of this was that it was extremely difficult to choose between applicants.

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Appendix 1.

Job Description





Job title

Peer Worker for Employment Related Personal Development

Hours

(X) hours per week



Salary

£X.XX per



Contract

(X) Years



Location

Bristol

Peer Workers will meet with members in person at one of Keyring's Hub locations.

Peer Workers will be required to travel to a Hub location to do their job.

Regional Manager

You will be working for the Regional Manager.

Your contact with them will be in person, over the phone and over email.



About KeyRing



KeyRing are a not for profit organisation who aim to support vulnerable people to live independently.

Keyring do this by helping people with things like housing and money.

KeyRing listens to and works alongside people in their local communities.

KeyRing work in 35 areas across England and North Wales.

Job details



This is a paid job for a person with a learning disibilty.

This is a new kind of job that involves Peer Work and has been made with KeyRing members.

Peer work is when people with similar experiences offer support and understanding to each other.

It is all about building and keeping relationships.



In this job you will work to:

 Use your own experiences to have supportive and empowering relationships with KeyRing members

 Support KeyRing members as they look for work or volunteering roles

 Support KeyRing members to feel confident

 Support KeyRing as a whole by helping the organisation



• Use the "6 keys" to help make these relationships effective.

The 6 Keys to Peer Relationships



- The 6 keys are the 6 important ways to build a Peer Relationship.
- The relationship:
- 1 must build Trust

2 must be Safe and healthy


3 must be Friendly

4 must be built on Helping each other

5 must be built on Honesty

6 will take Time to develop



We think of similar experiences as the key ring that holds the six keys together.

The 6 keys are not the only things that are important in peer relationships but we think that they are very important.

More information about the 6 keys can be given to you.





If you are interested in this job

by post to:

(ADDRESS)



(EMAIL ADDRESS)





by phone at:

(PHONE NUMBER)

Peer worker for employment - Person specification



There are lots of different ways to build peer relationships.

This is because people have different strengths and do things in different ways.

We think it's important to start with what you can do.

On the selection day, we want to learn more about you and your unique ways of doing things.



We are interested in your potential to do this job well.

My experiences



Peer relationships are built around shared experiences.



We are interested in your potential to think about and talk about your experiences.



We would like to learn more about how you might use your experiences to connect with other people.

What do I have to do?



You will use the six keys to help you to build relationships with KeyRing members.



The six keys to building peer relationships are:



1 must build Trust

2 must be Safe and healthy

3 must be Friendly

4 must be built on Helping each other



5 must be built on Honesty

6 will take Time to develop

How do I do it?



We are interested in your potential to use the 6 keys to build peer relationships with Keyring members.









We would like to learn more about how you might do the following things:

1 Build trust

2 Be trustworthy

Keep relationships safe and

3 healthv





Be friendly 4

5

Be honest

6 Be yourself

7 Take time and have time



8 Keep to time

Give and take to share the

good things from relationships

How do I fit in with KeyRing?



Right

To do this job you will have to follow Keyring's values.

These values are very important to KeyRing and the work they do.



Keyring's Values are:

1 Equality

2 Rights and Respect

3 Inclusion and Influence







We would like to learn more about what these values mean to you and how you might put them into action in your work.