Co-production – how disabled people can (not) break the mould in service / workforce development and commissioning

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Content

Executive summary

This position paper is about **user-driven commissioning (UDC).** Most of the examples and thinking are from a joint research project, which Disability Rights UK carried out with the University of Bristol from 2015-18. The aim was to explore the ways disabled people can have an influence on commissioning.

What is UDC? UDC should be controlled by disabled people, working alongside professionals. Services for disabled people are selected and evaluated according to the outcomes disabled people have defined for themselves. UDC is more than just peer support, even though the peer principle is at its heart.

How do we know if UDC is working?

1. UDC recognises disabled people as assets.
2. It builds on people's existing capabilities
3. There is a reciprocal, mutual relationship between professionals and disabled people
4. Peer support networks are at the heart of the process
5. The distinction between professionals and service users becomes blurred.
6. Public service agencies become facilitators, rather than delivering services to disabled people.

We found many barriers to successful UDC.

- Disabled people were sometimes invited to become involved on an ad-hoc basis, without knowing each other, and then expected to adapt to inaccessible processes and management styles. This can result in mere rubber-stamping of pre-made decisions.
- Organisations of disabled people were losing funding, and had less scope to share insights, feel connected, and influence change.
- Statutory service providers can become rigidly focused on internal systems. At the extreme, they see 'engagement' as something that can be gifted to disabled people, and commissioned out to consultants.

- There may be little time for disabled people to form as a group, and learn to trust each other, before jumping into action.
- Definitions of disability can be a barrier, since medical terms about specific impairments can weaken the impact of collective action.
- Disabled people do not always get the support they need to keep going with UDC or co-production, which is a long process.
- User-led initiatives can become professionalised, and the 'disability' focus can become lost in a more generic Equalities framework.

In general we found UDC worked well when:

- There was a system to offer unconditional support to disabled people, with upfront commitments.
- People aimed high, created a vision and set tangible milestones.
- There was respect for disabled people to allow them to persist in making their voice heard. Challenges were seen as positives.
- One user-led organisation could learn from another.
- Disability was seen as an 'asset'.
- Disabled people's organisations sometimes ran services.
- There was time for an 'inward' phase for disabled people to build up their own vision, as well as an 'outward' phase for them to contribute.

Recommendations

1. Provide and seek facilitated space to look inwards and self-explore and also form conditions for self-representation and impact.
2. Accessibility and co-production go hand in hand – not one comes after the other or can ever be 'ticked off' as completed.
3. There is a requirement to be flexible when making improvement but seek to widen the scope of change (of a project) only so much that the system can (still) make specific, meaningful and effective upfront commitments to people.
4. Provide and seek impact in defining outcomes ('what does good look like?') but also in finance and contracting models ('which outcomes does the provider need to achieve in order to be paid?').
5. Source and keep alive opportunities for co-delivery as well as in overseeing, mobilising and monitoring provider contracts.

What is this position paper based on?

Most of the material which this position paper is based on was gathered as part of 'Getting Things Changed' (Tackling Disabling Practices: Co-production and Change in user-driven commissioning) – a three year research study http://www.bristol.ac.uk/sps/gettingthingschanged/ funded by the ESRC (Economic and Social Research Council). The study started in April 2015 and ended in May 2018, and its fifth strand relevant for this paper focused on **Disabled People as Commissioners** https://www.disabilityrightsuk.org/user-driven-commissioning

Commissioning means going through an ongoing cycle of defining what support people need and then buying and reviewing it – weighing up (low) price against (high) quality. Once contracted, services are often being paid solely on the basis of activity, i.e. what providers have 'done'. A more innovative approach is to select and pay services on the basis of the actual outcomes 'achieved' by professionals and disabled people together. User-driven commissioning (UDC) supports this turn towards outcomes in a way that is from start to finish controlled by disabled people and patients alongside professionals. There are many barriers to co-production in commissioning. Therefore, disabled people informing and leading aspects of service and workforce development can be meaningful and effective stepping stones on that way.

What problem is at the heart of this position paper?

Systems and people
Many different systems for providing support, care and health services have been established in the UK and then taken through reforms in the last decades. Often this has been with the best intentions but the various overarching – implicit or explicit – imperatives between 'doctor knows best' and 'putting people first' are certainly confusing and have the overall effect of maintaining the status quo of tokenistic rhetoric in place of substantial co-production. So far at least it seems that the personalisation agenda as driven by the system has not paved the way for a coherent, radical overhaul in the shift of power to the people.

There will most likely be objections to the distinction (throughout this position paper) between 'systems' on the one hand and 'people' on the other hand – after all, are not all systems made up of people and are professionals not also patients? There are indeed some (temporary or

permanent) overlaps but what matters most is what resources 'people' have available and to which degree they have become part of or had exposure with the system (often at the price of losing some 'people' or peer identity). The word 'system' rightly suggests something bigger than an individual. Understandably at times of vulnerability and of needing care many 'people' consciously or subconsciously want to subscribe to that bigger entity 'system', ignoring one's own (people) power and the power of co-production for better health, well-being and independence.

The 'material' differences between patients and professionals may shift but don't disappear; for example, compared to 'common' patients there is far more capital and influence available to such patients who happen to be paid representatives of a health charity working with government departments or who successfully took legal action against the system for misdiagnosing early symptoms of cancer. At any rate, the increase in political and professional stakeholders, service frameworks, best practice principles and policy imperatives (such as those in the most recent NHS Long Term Plan) has not only created improvements but also furthered barriers for people using services, sometimes destroying the very foundations for self-initiative, coordinated care, independent living and peer support. It is therefore argued here that systems and people should not be merged but deserve attention in their own rights.

Personal (health) budgets and Direct Payments have had a great impact in redressing this imbalance of power – by paying out money following a support plan and resource allocation and hence allocating far greater levels of choice and control directly to the individual. In some way this shift has placed an unfair and unacceptable onus on people. Nowhere has this become clearer than when holding disabled people responsible for back-paying their personal assistants for overnight support in the past (Voluntary Organisations Disability Group, 2019[1])– a fatal shift of accountability from the system to the individual.

As far as collective involvement is concerned, there are different views on how and at which level people should be paid for their work in service / workforce development and commissioning, and no doubt there can be numerous practical challenges which go beyond the scope of this paper. At any rate, payment on a unit basis (half a day at £50) can in itself distract from the need to influence 'outcomes' and bring about positive change as experienced by people – rather than just reflecting traditional line management. A better perspective may be for the system to

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[1] https://www.disabilityrightsuk.org/news/2019/march/vodg-demands-clarification-overnight-case-support

commission an autonomous user-led organisation (ULO) for peer support on the basis of outcomes. By definition this ULO would have to be accountable to its members, perhaps in more innovative ways. No doubt, the need for improvements cuts across all life domains, way beyond the key focus of this research strand on health and social care. As confirmed by the recent report on the UN Convention for the Rights of Persons with Disabilities (UNCRPD): Access to the built environment has worsened. Support has been cut to maintain personal care only and make residential care compulsory where this appears more efficient. There is a rigid approach to assessment and monitoring for Direct Payments with less flexibility and a rapid rise in number of compulsory treatment orders. The failure to act on the ongoing investigation ofthe deaths in hospital of people with learning disabilities continues as does the lack of access for disabled people to preventative health care, frequently leaving disabled people to their own devices in place of coordination of care and support. The Care Act contains a very general wellbeing principle but not an independent living principle. One may argue that disabled NHS staff are even worse off with a greater likelihood of facing bullying and harassment than any other protected characteristic group.

This position paper cannot shed more light on all these deficiencies but it seeks to take stock of the different (limited) forms that co-production can take in response – by bringing to life what it may actually mean to 'set a shared purpose' as stated in common co-production guides as first 'step'. There may be many waves, cycles and throw-backs towards such a shared purpose which requires the building up of trust and openness on all sides towards real, equal partnerships so that health, well-being and independent living become a journey we all feel part of. There will be different views on how to bring about real improvements, and any challenges should be actively explored at all times. Therefore, this paper goes on to set the ground first before attending to more specific barriers, ambivalent actions and drivers for co-production. It is not a cookbook but aims to illustrate key parts of such a dynamic and non-linear journey.

What is in it for systems and people?

Co-production has the potential to marry up the effective elements of well-developed statutory systems with the expertise of people knowing how to live their lives to the full with and despite of disability and long-term conditions. Disabled people are experts in mastering crises from birth or from diagnosis and have learned to manage change every day –

similar to those changes faced by frontline teams or larger system-wide interventions. There are productive synergies between these distinct crisis responses: services need to reflect real needs and aspirations and become more directly accountable to people to whom the NHS and social care belong since 70% of NHS expenditure are on disabled people[2]. To achieve this, the system needs to enable a rights-based approach and real ownership of services and support by patients, communities and disabled people.

Peer support has been a natural response in the disability movement for decades if not centuries, yet how it works and what it needs is hardly understood and incorporated by the system. Peer support is one of the greatest 'interventions' and most powerful at diagnosis and crisis points when the person is most keen and susceptible to hearing from someone who has travelled a similar path in the past and has succeeded just a little further. Peer support is often the one factor that can explain why one person with the same diagnosis can live more independently and feel so much better than another person with that same diagnosis. Conversely, the inaccessibility of peer support at crucial stages can lead to passivity and dependence coupled with deteriorating health outcomes.

Peer support can act as a vehicle to self-management but the system tends to exploit this idea and hence mostly fails as the 'whole' life domains of an individual patient are ignored. A narrow focus (by an organisation or an employer) on peers doing the job as volunteers (for example promoting hospital discharge or selling the benefits of a disabled staff group) will fail if no efforts to build a holistic environment where people feel safe, welcome, engage and pick up ideas from peers over a longer term has been created beforehand. There is a fine line between opening up to (or initiating) and formalising (or replicating) peer support. Peer support and peer-led communities cannot be managed and scaled up like a traditional service but require the commissioning of positive environments that are conducive to and are nurturing corresponding qualities and behaviours in all players.

To this end, statutory systems need to go beyond the surface and genuinely build on how people lead their own holistic lives – with and irrespective of any long-term condition. There have been thousands of such tacit opportunities of people expressing ways forward and taking leadership (in this programme of work alone) most of which have not been identified let alone used. Improvement by co-production is a

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[2] Fact and figures, Disability in the United Kingdom 2018, Papworth Trust, 2018

mutual, sensitive and multifaceted process. At a formal level – much further down the line – peer support and self-assessment would become taken-for-granted components of every commissioned care pathway from help-seeking through to conveying diagnoses up to end of life care.

What is the basis to genuine co-production and what can it achieve in commissioning?

This journey requires disabled people to plan the (integrated) services and support they and their peers need – from the start, giving way to how people self-assess their needs and what types of support they imagine to achieve agreed outcomes. Local systems should be designed to support people to that effect, including the flexibility to question and actually open up routines to draw on advice and (peer) support from other areas. NESTA has defined co-production[3] as *"delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change."*

Six principles[4] follow from this against which this position paper may act as a kind of practice test:

Recognising people as assets: transforming the perception of people from passive recipients of services and burdens on the system into one where they are equal partners in designing and delivering services.

Building on people's existing capabilities:

altering the delivery model of public services from a deficit approach to one that provides opportunities to recognise and grow people's capabilities and actively support them to put these to use with individuals and communities.

Mutuality and reciprocity: offering people a range of incentives to engage, which enable us to work in reciprocal relationships with professionals and with each other, where there are mutual responsibilities and expectations.

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[3] *The Challenge of Co-production*, NESTA and new economic foundation, December 2009
[4] *Public Services Inside Out,* NESTA and new economic foundation, April 2013

Peer support networks: engaging peer and personal networks alongside professionals as the best way of transferring knowledge and supporting change.

Blurring distinctions: blurring the distinction between professionals and recipients, and between producers and consumers of services, by reconfiguring the way services are developed and delivered.

Facilitating rather than delivering: enabling public service agencies to become catalysts and facilitators of change rather than central providers of services themselves.

From earlier work we know that co-production is about developing creative ways to empower the person and carer as partners at every stage in a complex care pathway and recognise and build on their systems of self-directed support, eg at hospital admission and discharge. Many thousand individual, co-produced care packages pave the way for a generic, collective perspective. A wide range of people across impairments and carers should be listened to, valued and invested in on their own terms and for the longer term. However, most of what people say does not translate into a formal process. A flexible approach that still has some teeth is required to gather fully people's experiences, needs and aspirations and ensure that what people say will help people improve health and well-being outcomes and take them closer to their life goals.

Partnerships resulting from earlier co-production have made people increasingly tap into their own informal support networks while choosing less intensive care and treatment options. Commissioning resources have been increasingly tied in with community support and there was therefore a better shared sense of what it is important to achieve and how to go about it. Further anecdotal evidence suggests that pooling personal budgets can shift economies of scale away from block contracts, with quality on a more equal footing with price, and peer support and self-assessment integrated into the local support offer.

Technology plays a key role and wherever possible, eg under the 'patient online' agenda, meeting points and virtual hubs should be co-produced so people can interact with both peers and professionals, eg when writing symptom updates in their records (reducing late diagnoses or even misdiagnoses). Outcomes for contracts need to be defined in terms of independent living as reported by people rather than guided by straightforward benefits which would only be convenient for the system.

Health and Social Care have become more conducive to the principles of co-production, as reflected in the individual and collective involvement duties in the Health and Social Care Act. There has been heavy borrowing of activists' language to bring about change bottom up with references to 'choice', a 'social movement' and 'peer-led communities' for example in the NHS Five Year Forward View. It appears indeed promising to quickly reap the benefits and win-win situations that co-production can have for systems and people; for example, Direct Payments do not only transfer spending power to disabled people but also make spend more transparent than if it was buried in large block contracts. Capitated budgets under Integrated Personal Commissioning (IPC) are intended to take this spirit further by bringing together large cohorts or groups of people who share specific needs across a whole region – paying providers on the basis of co-produced outcomes for whole cohorts of people (with complex or mental health problems for example) instead of activity. Recent developments seek to introduce personal budgets beyond health and social care in order to enhance choice and control in such diverse areas as maternity, employment and (re-)offending.

However, it is very easy to fall into the trap that the system – inadvertently or not – sets out the terms of that journey for disabled people to simply follow. This somewhat hidden paternalistic approach would be facilitated and not challenged by the many consultancies, research bodies and think tanks operating in this field who almost exclusively seem to talk to system representatives rather than people, thus failing to acknowledge and build on the origins of the disability movement.

Why did the focus on co-production have to be extended beyond commissioning?

In the project discussed in this paper, we aimed to explore the different ways people can have real impact on statutory systems and processes – including actual service changes, professional styles and attitudes of managers and frontline staff as well as their own health outcomes and independent living. Projects should have the opportunity for some independent facilitation to foster genuine dialogue and mutuality between people and systems. Commissioning was supposed to be the one and only formal and measurable anchor point for people to reach the real power of spending substantial health and social care budgets.

From the perspective of people, the intended reciprocity requires some time to look inwards before articulating and translating needs, preferences and aspirations into the system instead of just responding on the go to a 'ready-made' power point presentation on person-centred care for example, and this flawed misunderstanding of reciprocity between people and the system has probably been the biggest barrier. We had a very helpful challenge from a member at an early meeting of the Advisory Group for taking too much of a systems' focus – after all, 'commissioning' means the statutory practice of buying services within a legal framework and competitive rules-based market, easily pushing away the hands-on everyday insights and considerations of people with support needs.

In this formal and somewhat overburdening situation of commissioning, people may long for structure prematurely even if far greater gains could be achieved by allowing the creative flow between shared leadership, passion, dwindling interest and full choice and control by disabled people. It is important to actively watch out for genuine opportunities for the system 'to let go' and be open, creative, patient and flexible without relying on externals acting as convenient proxies to disabled people.

In order to help create some common ground and 'combat' this systems approach, we he had set some design principles and milestones that should work for people – as outlined in the forthcoming section on 'drivers for co-production'. We hoped to have made effective space for people to explore, gather and translate into the system "what do I need to feel good about myself" (with or irrespective of any condition or care area at stake). This has been with a view to ensure that services are paid not for activity but for real improvements in how people themselves report defined outcomes achieved together so it matters what and how people feel and not simply 'how often' people are seen by professionals.

The reality of co-production on the ground soon taught us that we needed to widen our approach to go beyond our definition of user-driven commissioning. System representatives regularly felt not at ease with the official support from a national campaigning organisation and with taking on a local Lived Experience Team and ensuring that team would be able to have clear and defined inputs across 'their' commissioning cycle. This reluctance meant that we had to widen our definition and include every attempt or initiative where a group or team of disabled people (more than two people meeting already for some time) had a reasonable chance to get things changed, i.e. be self-represented and connected and have voice and impact or at least 'a foot in the door'

of the NHS or local council – way beyond the confines of commissioning. This widened perspective eventually turned out to be beneficial. It enabled us to include disabled workers who – by employment – had a connection with the system even if this did not necessarily mean that disabled workers would particularly succeed in getting things changed.

Findings

There was a great deal of ambivalence in the dynamic steps taken by the people and the system towards and away from each other, and this is why there is a separate section on this ambivalence after addressing barriers and before addressing drivers for co-production.

Our field ranged from emerging and fully established user-led projects to disabled staff groups and statutory sector NHS and social care organisations supporting a group of disabled people. However, none of the statutory organisations found its contribution beneficial enough to be named here. Most user-led projects in turn may fear worse prospects if their struggles were exposed.

Most of the barriers, ambivalent actions and drivers encountered are in fact convoluted, even though they are presented here separately and in turn. Therefore, a simple, pragmatic time-based structure is used to focus on the beginning, middle and ending of projects and associated (team-building) stages of forming, storming and (attempts at) norming; the last stage of 'performing' has not been reached here. There is also an unresolved, basic dilemma with 'projects': a project is commonly the unit through which change is delivered in the systems world. Yet, people themselves articulate the need for change in many different ways time and again, not necessarily taking the form of projects. At some point, however, lasting change would be formalised in contracts and rights.

Disabling practices (barriers)

People thrown together to fix ad-hoc system needs

When it comes to collective involvement it matters who invites the other party to the table and when and how this happens. Frequently, people are invited ad-hoc as individuals not knowing each other and then being expected to adapt to inaccessible processes and management styles,

simply to rubber stamp decisions and policies that have already been set. For example, there has been a keen interest in working with this programme on the different ways 'patient choice' could be promoted more effectively – there has been no such interest in giving people the space for co-producing the actual options for such choice in the first place and how delivery could be overseen most effectively together.

People assemblies without meaningful agendas

As long-term grant funding for a diversity of user groups and projects has decreased, there is far less scope for people to gather and give each other voice, to share insights, be connected and feel represented in order to articulate the need for collective change and then influence the system as a direct consequence. Some peers (eg people with learning disabilities) are supported with practical help to meet each other over longer periods but hardly get together with actual decision-makers which would really build up their skills, confidence and – crucially – impact on the system. For instance, a group of young people with learning disabilities has identified 'swimming' (when they wanted to and with as little interference as possible) as key outcome for them to achieve. Why would it not be paramount to negotiate solutions and positive risk-taking together with the concerned people with learning disabilities? It was apparent that the system assessed operational challenges but not the opportunities for people. The actual risk (of an accident at swimming) seemed to overshadow everything else. It felt there was a climate of protecting the status quo by making subtle hints with evidence-based practice only being considered when this suited set agendas. Unsurprisingly, in this climate, the most dedicated professionals lacked support from system leaders, management and resources to make working together a success – with the best ideas and solutions often going unnoticed.

The system playing up its overburdening infrastructure

There is often a rigid focus on internal systems, processes, established evidence, protocols and timescales out of anxiety of engaging with the real world and people 'outside'. This was felt as a clear rejection of 'raw' people and their voice. Instead of direct encounters, the system can show a comfortable yet unhelpful service mentality: 'engagement' is commissioned out to agencies or consultants who are only remotely connected to either people or the system. Or there can be individual

senior managers possessing and displaying nearly perfect rhetoric of personalisation which can act as a tricky barrier: firstly, spoken words are easily confused with actual delivery; secondly, any challenges from service users are immediately diverted without even the chance for a (potentially very helpful) confrontation. No wonder that the NHS E Insight Strategy is solely focused on building the insights and capabilities of professionals – overlooking the much greater potential of a user-led perspective of investing into the insights of disabled people (with a view for them to actively and directly shape the system). This inwards-facing perspective was only topped by the approach from a highly acclaimed support provider giving out community vouchers (for cinema etc.) to reward positive behaviour by its service users. So much to where the system still perceives the deficiencies to prevail.

All this leads the statutory sector to conduct itself as a faceless 'gifter of resources' instead of taking substantial efforts to include people directly from the start and facilitate an exchange that is open, fruitful and effective for both. Even legal constraints and EU procurement rules are sometimes presented to justify the lack of involvement or co-production, for example when declaring it impossible to share the content of bids and contracts with people who use the services concerned – as if people could not be trained and trusted just as any paid staff and board members can.

Jumping into action without forming as a group

It is an integral part of systems that they thrive to set out project plans, make a visible mark and allocate roles – often without allowing for the dynamics of change people themselves bring to the table. For example, there was an NHS Trust showing premature overconfidence in making a call to disabled staff for them to become peer supporters (for patients with long-term conditions) when not a single disabled staff member had even been identified, engaged with and then reassured of why such peer roles would be beneficial to themselves. It is certainly true that disabled staff groups need clear issues to solve and be supported by clear 'terms of reference'– just as any other group of people with shared needs and aspirations. However, time and again, people do not feel that the required trust has been built up before a purpose could be teased out and agreed and (then) any outcomes be co-produced together.

Interplay of identity, cultural and organisational issues

No individual is only 'disabled' – and people take offence at such an implicit or explicit suggestion. Strictly speaking, disability should not even be one of the nine protected 'characteristics' under the Equality Act such as race and sexual orientation because disability is a situation one finds themselves in – not something someone 'has'. This is reflected in the Social Model: not the person but the environment has to adapt so that the person can live their life to the full as much as everyone else.

When it comes to promoting equal rights, involvement and 'user-driven' commissioning, it is helpful to agree a common name or category shared by those seeking positive change. Indeed, many people share the experience of having to 'misfit' into society and its infrastructure. Often, people find they can ascribe to the term 'disabled' if there is sufficient room for personal exchange and discussion under their own terms. Also, using the term 'disabled' comes with more straightforward recognition and legal entitlement to support to those with a physical or mental impairment that has a 'substantial or long-term effect on the ability to do normal daily activities' (as defined under the Equality Act).

The question really is if any definition or common ground is too narrow or too wide in order to appeal to peers AND make the case to systems. At any rate, referring only to specific impairments (borrowing terms from the medical world) can easily weaken the bigger, shared case that comes from unifying across impairments. On the other hand, there have been calls to open up (disabled staff groups in particular) to push for improvements on wider (staff side) issues such as general burn-out and work-related stress and even to people with (temporary) broken legs. This extension may help increase numbers but conflates the distinct perspectives of long-term and profound disability. 'Disabled' may act as the most accurate and succinct term and provide some common ground even if this is not made explicit and does not unify people at the start.

The emphasis on where a group wants to go and what it wants to achieve can be crucial to build up social capital and networks with allies be they disabled or non-disabled. For instance, young people may prefer to call out what they do or aspire to together rather than reproducing the label 'disabled' which is why there are social media, 'stay out late' or swimming groups. This focus on the future is not intended to play down the widespread experiences of discrimination and bullying but is an

attempt to redirect attention to what people can do rather than what they (allegedly) cannot do.

Resistance, dwindling interest or capacity not picked up

The above barriers can easily combine and destroy co-production right at the outset – almost always because the system fails deliberately or conveniently to understand and provide the specific support needed in the process. Co-production is a long (if promising) journey with systems and people crossing a number of emotionally and physically effortful milestones together. Resistance and dwindling interest or capacity seem almost inevitable, and so these 'kicks' need to be picked up and explored. As long as this does not happen it is not surprising that disabled staff and networks of disabled people try to regain control by shifting back to passive recipients of services. It is unfortunate that such retreat or inner exile can meet with the concerns of some professionals about burdensome expectations on 'disabled' people (and themselves), equating attempts at co-production to tick-boxing, which helps box off established roles and the 'way we do things here'.

It is important to stress again that there is no level playing field between the system and people. Without independent facilitation people may tend to take any offer of involvement as genuine and embrace it or pretend to do so in an inner exile. There can also be too much inwards focus so that the opportunity for changes to the system can be missed and no outwards impact be achieved. It is an absolute requirement for everyone to be willing and keen to share and embark on co-production with disabled people being funded to build, raise and bounce back and forth ideas. Numbers matter, there are many disabled people in many places, and working on numbers increases the stakes as one disabled NHS worker pointed out: "NHS staff feel safer if they know that the NHS Trust supports ALL disabled people, and vice versa patients can benefit from hearing how disabled staff have gone about disability themselves."

Break it up or integrate?

Some initiatives that had started as user-led became professionalised with no disabled person or even the term 'disabled' featuring anywhere any longer. At the root of this there may be hope for better commercial prospects by building on more generic 'positive' terms or by appealing to

the established and convenient connections of the new (non-disabled) chief executive. Trade unions have a natural interest in appealing to (new) members and also in making their customer relations more manageable by cutting across the various forms of social stratification. Intersectionality as an approach puts disability alongside race and class, etc., as these characteristics are all woven together and affect people in their multitude. This certainly helps clarify origins of discrimination and foster good relations but also risks losing the distinct perspective on disability in its own right. These pros and cons need to be weighed up.

Charities or 'voluntary sector organisations' increasingly pick up on disabled people's insights and develop new models not just in public service delivery but in claiming specific expertise in supporting people to live their own lives – without proper investment in co-production. This can result in disabled people being excluded by such 'proxies' from community development, local commissioning and national government bill teams in the law-making process.

Disabled professionals can find themselves tempted to ease that tension (between 'disabled' and 'professional' / very able) in their lives and break up with the perceived burden of 'disability' and instead focus on their career as a nurse with a 'small', hardly noticeable impairment. Instead, unifying around and consolidating the experiences of disability could help systems and people develop and use more effective support.

Actions with ambivalent outcomes

Building the cause but not getting through to decision-makers

Many disabled people have met (and continuously invite others to join and speak) about shared issues. People work hard to improve their lives as individuals and strengthen our newly formed or established user-led organisations. For any collective action or social movement it is key to spend time to explore and agree 'where we come from, where we are and where we want to be'. This has led to lists of overarching independent living needs and aspirations, compiled in many local areas.

Corresponding activities are about building a base and clarifying the cause: producing articles for community newsletters and hanging up

posters to attract more people, talking about (positive and negative) experiences, the need for a group, how to get more people to join in other ways, etc.. These actions do shift cultural barriers:

A young people's forum approached a consultation (which it was asked to carry out by the local council and CCG) as a means to raise its own profile and showcase to the wider local public what it does and is able to achieve as lived experience experts in peer and self-advocacy. New people coming on board already makes a difference to the well-being and confidence of the forum and its members.

Peer interviews have also been conducted to inform local or regional strategies. The problem here has been that the findings have often not been related to concurrent action plans. Perhaps there is some explanation behind the term 'outreach' which is still used by many organisations for their processes and roles – who defines what the centre is? Why is the system not reaching 'in' to where people are? This arbitrary boundary may help people feel included in ad-hoc and random local debates at the price of missing out on setting the very context for the real actions taken in top-down service directions, commissioning / procurement exercises and contract review management.

Threats and opportunities for disabled NHS workers

In an employment situation 'self-declaring' disability can be particularly difficult. Nevertheless, making a start with that declaration at recruitment or during working life acts as prompt and in fact legal requirement for employers to take action and improve disability equality – without such a declaration, employers can escape their legal responsibilities, unless 'duty of care' comes into play. Owing to their employment contracts, disabled workers seem a step closer to the system. This provides the opportunity to go around with open eyes and pick up, identify and address the 'real' underlying issues, if Disabled Staff Networks would only be supported effectively. Before self-declaring disability, candidates and staff should be reassured by the employer's support. Some peers and staff groups have taken on this role and accessed HR systems, produced stories of disabled workers and printed them off for noticeboards in order to spread the word and find more disabled peers in the organisation (as commonly 50-60% of staff don't access electronic profiles / emails). Previously staff could also be reminded on their payslips of the possibility to self-declare disability but this does no longer seem to be possible for technical and legal reasons.

Disability opens up conversations and paves the way for improvements in complex situations but this is often neither understood nor handled well. For instance, disabled staff in the NHS can find themselves in a double-bind – as professionals, they are bound to put their 'personal characteristic' last and be strong and confident to serve the patient; as disabled staff, they may themselves require reasonable adjustments to perform their roles (which breaks down some of the divide between professional and patient and hence risks some professional clout). There are ways for disabled staff to regain professional clout and build on disability as an asset, which will be addressed in the section on drivers. Some employers recognise the need for a disabled staff network to have 'freedom to act', for members to be released for a specific amount of hours per month and set its own strategic goals, terms and actions – instead of simply delivering agendas given from the top, such as under the Department for Work and Pensions' 'Disability Confident'.

Nevertheless, even if some disabled staff are released to support the networks, there is still an imbalance towards the system, perpetuated by often tokenistic, corporate approaches such as key performance indicators (KPIs) under traditional line management rules. Such indicators relate to disabled staff only indirectly (eg number of senior managers undergoing training on 'unconscious bias') and have far less impact than alternative co-produced metrics could have, especially if they are also directly overseen by disabled staff.

Scoping out change – aligning the dynamics between strategy and hands-on improvements

For some groups of disabled people there has been quite a lot of information to consider about where they were and where they wanted to go. There is some value in coming up with clear outcomes at the start, i.e. what is it exactly that we mean by improving our lives? Is there a certain action we want to see? Or how would a desired change make us feel? For instance, as stated above, there was a group of young people with learning disabilities who identified going swimming (at a time they wanted and not having planned sessions cancelled) as a key outcome to be supported by the local (high-level) Learning Disabilities Strategy. This challenge could have sparked an open-minded conversation, and there is simply no reason why a strategy should not include such hands-on outcomes or even depart from them to keep the strategy and actions

grounded. Yet, systems have 'learned' to fend off such challenges by drawing on processes for reviewing Direct Payments spend, safeguarding and unmovable terms in agency contracts. Sadly, this reaction has not only declined the requested change in swimming support provision but also undermined the general confidence in people to raise productive challenges.

Conversely, focusing on a strategy can lead to greater impact across a whole system – as opposed to some dispersed roots and shoots of improvement. For instance, the Workforce Disability Equality Standard (WDES) aims to give disabled staff (and local communities) the ability to hold NHS organisations to account by means of a transparent structure to making improvements, using a consistent, standardised framework across the NHS. Here the very valid question remains if this standard can over time become sufficiently sensitive to the everyday experiences of disabled staff and if the standard fosters people's confidence to raise and improve matters effectively. On the back of the standard employers may feel more prompted to take action and show disability at work in a positive light ('disability as an asset'). This alone could open up conversations in the NHS and with local communities. As a result, more disabled workers would feel safer in declaring disability and applying for a job in the organisation which in turn would make more peers come forward and join in. In this way a strategy can set the tone for an environment that is more conducive to supporting the specific needs and outcomes disabled workers have, want and bring.

Strategies have limitations and can sometimes be counterproductive. In everyday life disabled workers often find themselves having to reconcile individual with organisational needs. This can mean negotiating some individual improvements at the price of undermining some collective, legal or policy achievements and accountability. There is almost always a tricky balance to take between formal and informal approaches in declaring disability and requesting reasonable adjustments:

Disability is a situation one finds themselves in, and so it matters how one approaches this same situation and what the response is – time and again. For example, in one project site disabled worker K.N. spoke about her sensory impairment and struggles to climb stairs. K.N. had a good relationship with her line manager and felt supported at a personal level. However, from her observations (as disability staff group chair) many peers were reluctant to mention health problems at appraisals with their line managers, and this shaped the feeling of isolation in the organisation. K.N. decided to act as a go-between for a deaf colleague

without support – by informally approaching a different, more empathetic manager. This approach was deliberately made not in writing in order to get things started outside of processes and in order to not expose the actual line manager. In reflection, K.N. feared she may be complicit and help perpetuate a certain culture of silence and focus on self-help as the only course of action. K.N. realised how immersed in this she herself already was: "my boss encourages me to not make a fuss when going up stairs, and in turn I can have my day working from home away from the open-plan office I sometimes struggle with."

Do such informal approaches improve the situation for the individual disabled person at the cost of perpetuating the low status of collective agreements? A healthy and open-minded organisation may identify and embrace positive solutions and seek to replicate them across the board.

Routes to direct impact – forming, storming, norming and performing

This section draws on a concept from developing teams since – ideally – co-production involves a kind of team coming together and acting on a shared cause. A lot of the drivers in co-production between people and systems relate to group development. For teams there are four stages "forming, storming, norming, and performing" according to Psychologist Bruce Tuckman[5]. At the forming stage, people and systems usually get together for the first time, have different expectations and feelings towards each other and after a while may recognise what aims they have in common and start to tease out roles and responsibilities to get there. Storming emphasises the need for questioning and pushing boundaries and working styles which is essential for productive teams as well as for open-minded and open-ended co-production projects. At the norming stage, people and systems start to respect and resolve their differences and turn to shared goals but may still slip back to storming as new tasks, issues and problems arise. Finally, performing relates to achievements – this stage has not been reached here as supporting structures and processes had not been set up or maintained effectively enough.

In co-production there are no traditional teams and no fixed boundaries which makes the transition from one stage to the next even more complicated: systems and people have key differences in meanings, materials and competencies. In order to map out successful co-production

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[5] "Developmental Sequence in Small Groups", 1965

journeys, some of the previous threads and examples on barriers and ambivalent actions are picked up here and loosely categorised into Tuckman's first three stages. The main perspective in this section is on user-led change; this does not mean the system could not initiate change, although the trick probably is to actively search for and give way to user-led change by tweaking any major co-production programmes accordingly.

Forming

System to offer unconditional support with upfront commitments

It is probably for the system (in its different guises) to get the ball rolling and find and tie in with any groups or projects people may have set up already. User-led change is already happening – it must just be nurtured and supported with a dedicated, hands-on approach. This can initially mean as little as sponsoring weekly meetings on a specific topic, paying for transport, food, facilitation (if requested) and people's time.

Signing up to one or two hands-on improvements (or problems to be addressed) in specific areas and in positive, mutually beneficial ways right at the start will help everyone build up trust, focus and confidence. This would add flesh and bones and an essential ongoing practice test to any emerging strategy in the longer term. It is important to build real if loose early connections and strike the balance between relevant lines of work such as service directions, commissioning, contract management and people's natural curiosity, expression, pace and drive to achieve.

Mutual training should go alongside this to integrate the 'other' side. People should be invited to act as (paid) co-trainers from staff induction to patient rapport and conveying difficult diagnoses for example. Professionals may become ambassadors for disability groups bringing together issues affecting staff and patients. The NHS in particular could pave the way by supporting their disabled staff when it comes to planning, negotiating and taking a set of actions on Disability Equality for and by themselves – with positive knock-on effects on patients.

Aim high, create a vision and set tangible milestones

A truly co-produced disability strategy needs to be overarching in improving outcomes for and with disabled people. It should combine attempts to draw on wider policy with the insights from real local people. A strategy should also stipulate investment in collective rights, peer support and toolkits to build up visible role models and identify positive action and challenge discrimination. It is key for such information to be made available in ways that potentially reach all citizens in a local area and all health and social care staff, for example in the generic induction process of key local organisations. The information should include key contacts and examples to help people bring to life ideas on improvements in disability equality and make sense of what they may mean for themselves at different points in their lives. For instance, the system could suggest and then agree with people an area in which satisfaction (say with the Direct Payments review process) should improve (from 40% very happy to 70% very happy) in a set timescale. A set group including a Lived Experience Team could then think through, set and oversee the actions needed to achieve this goal together.

People pioneers chasing commissioners and providers

The above approaches describe a set of start scenario with the system knowledgeable of and in open arms towards co-production. In real life co-production mostly goes back to and relies on people's perseverance to be heard and have their wishes acted upon. Such perseverance pushes for the required mutuality between the system world and how people live their lives.

Finding out about how existing services are being provided and commissioned is key for people acting as pioneers for people power – an endeavour that is particularly challenging at present with boundaries and responsibilities continuously changing between Clinical Commissioning Groups (CCGs) and local councils (following the NHS Long Term Plan). Having developed a basic understanding of the landscape of services, an entrepreneurial spirit helps: what can we do better than what is currently on offer?

For example, in one project site a group of people with HIV took this to an impressive length: at the start people felt pushed around. If there was any support available, this was fragmented with services opening and

closing down in short sequences. Furthermore, the set protocols and routines of that given support hardly resonated with how people lived their lives, failing to bring together medical and social aspects of managing HIV and beyond across whole life domains. So people thought they could build up and have a place they can go to, connect with other people and be involved. Empowering does not only go inwards but is very much about contributing to the community, too. The group picked up on specific requirements associated with HIV and found innovative solutions. This example will be continued under 'storming'.

'Our Area' (name anonymised) is a service user group run by and for people with HIV since August 2014, headed up by L.A.. It all started by L.A. looking for support as an individual. L.A. then met a peer support worker and went to an established NGO for training, and someone from another link group suggested to her 'why not establish a peer group in X? We can help you set it up'. The link group provided organisational support, eg in setting up the website etc. L.A. and her peers – all women with Black and Minority Ethnic origins – started a support group to help improve access to local support for themselves and peers with HIV.

What was support for people with HIV like before and how did 'Our Area' come into play?

Support for HIV was coordinated from the next larger town but people had to work around times that were made available by the charity service, often at short notice. In fact, L.A. sometimes had to act as go-between and tell people what slots had become available but hardly any people came. Then the service was re-tendered and a coordinator was tupe-d over from the old to the new provider D.

The initial purpose for 'Our Area' was to ensure some stability so people would have a reliable place to go to 'whatever comes and goes'. L.A.'s aim was to make people aware that it was possible to run a patient group and that they have a place they can go to, connect to others and be involved since L.A. built up the network and knowledge required: "We know what our needs are so if we are empowered enough, we can provide the services that we require for ourselves and work with people. A lot of people don't talk to other people about HIV but they can talk to peers. So it's about informing people both online and face-to-face and providing the space where people are involved and feel normal about the condition and once people build confidence

in that private space they will feel able to go a bit more outside and engage with life across all its domains".

Meanwhile, provider D approached L.A. because they were meant to provide support. L.A. agreed to support people with HIV at 'Our Area' initially but "we wanted to keep our independence". Peers received training on sexual and reproductive health but when they asked for travel expenses in addition to costs for venue and refreshments once a month (10 GBP), this was considered unfeasible.

Learning from service user peers to make links and cooperate

There is a lot of potential in picking up tips, tricks and insights from peers or fully-fledged user-led organisations (ULOs) who have travelled a similar path before. One example in a project site was about simply inviting a ULO to present how they go about co-production when providing Direct Payment support services. Sometimes, even such simple open exchanges are made difficult because the voluntary sector including many ULOs competes for the same limited resources and organisations do not have agreements in place to identify and respect each other's specific sets of expertise to cooperate. The focus on a specific issue – such as co-production in Direct Payments support with contractual deliverables – may foster open exchange and initiate cooperation by breaking out of competition (under set strategies and procurement exercises), discovering 'the whole is greater than the sum of its parts'.

Opening discourse on 'disability as an asset'

A new approach "Disability as an Asset' has been launched in the NHS in support of the 'Workforce Disability Equality Standard' (WDES) – helped by the work on the study presented here. Several disabled NHS staff acted as pioneers to look to disability as an asset, breaking the mould of traditional concepts of disability meaning deficiencies, i.e. NOT being able to do certain things. These peers proposed that they should be seen and drawn on as experts who often know from their own experience how patients (as peers) can be engaged, what treatments work and which are most cost-effective. This process often started with

peers (as part of disabled staff networks or completely outside of them) focusing on improvements for themselves personally (e.g. adjusted and better appraised jobs). After a while people realised that these improvements could be scaled up and become the taken-for-granted norm for all peers in the organisation and across the NHS. Taking this only a little further can mean to turn outwards and create the foundation for a focus on patients as peers with whom disabled staff can share a lot more than from the dominant professional perspective alone. For disabled staff this can mean to bring in a unique lived experience perspective and build up greater trust and rapport with patients.

For L.O., a disabled NHS Equality Manager, the approach to 'disability as an asset' could inspire everyone and work well for patients, too: "The trust has recently produced a flu jab video. This could have spoken to patients and disabled people a lot more directly (and boosted independent living and health outcomes) if staff with lived experience had been involved and brought in how they perceive everyday life – this would have ensured a real life perspective beyond the focus on complications which the non-disabled nurses in the video pointed out. In effect, 'disability as an asset' could bring both groups of disabled staff and patients together more".

Using the Social Model, L.O. felt the Trust could support (disabled) staff to redesign "how we empower disabled patients to be able to manage their appointments, treatment", etc. This would help with creating something like the 'Able Disabled Patient', linking in with related policies such as the Accessible Information Standard (AIS). There may be further knock-on effects from an initial focus of supporting disabled staff to make new connections with patients: "hopefully disabled staff not currently receiving support would say, what about me? and this would create a push for new support in turn".

Storming

There will be times of frictions with resistance as well as dwindling interest and capacity – more explicitly if people take things in their own hands, more implicitly if the system maintains control. Some would say open storming is inevitable to bring about real change, including the raising of challenges to norms and traditions that have been built up and internalised for a long time. There is certainly a drive to achieve with opportunities to open up to patients, disabled people and communities

and creative ways of swapping roles and breaking down unhelpful boundaries. However, this obviously corresponds with the fear of failure. Unsurprisingly, systems fear losing control and routinely check if there really is no return to how things had been before a user project started.

Building a user-led service

There is potential for co-delivery at frontline and strategic planning levels if information is exchanged freely and constraints are seen as chances. Building up a user-led service has become quite rare but still happens.

L.A. from 'Our Area' (supporting people with HIV) spoke of a great deal of fragmentation between services. Her understanding was that the local authority provided social support, whereas the NHS focused on clinical care – with some work commissioned out to charities as well. L.A. was not sure if these charities were commissioned by the local authority or the NHS and whether her project would rely on a lead provider as broker or could be commissioned directly by the Clinical Commissioning Group (CCG).

Once this was clarified, the provider charity D (holding the key contract from the CCG) began to challenge 'Our Area' for the low number of only four people on average attending support sessions, failing to understand that it takes time to build up rapport and trust for peers to be ready and come to Our Area on their own accord as opposed to attending a formal health appointment. There needed to be a space for people for whenever they would feel ready to take it up, and Our Area also needed to find people and support them on their journey to come to them. The charity argued that they couldn't justify the costs with such low numbers. L replied that the funding was for people with HIV so the provider needed to listen to them and develop support on that basis: "Rather than telling us what you feel our needs should be, we need to tell you what we need." All this was recorded by email to keep a record. The charity wished to consider this but has not got back for one year after that. L complained that the provider's logo should be removed from the website of Our Area with no partnership-working happening and no funding forthcoming (a barrier to other funders).

L.A. then approached the local clinic directly with an update on progress while obtaining information about opportunities for peers to be involved in the services. The clinic required consistency so they could refer people safely. At an information day both 'D' and Our Area

as independent patient group were invited which indicated that there was now a level playing field to be established.

All members of Our Area trained as peer mentors through Positively UK but new concerns on patient confidentiality arose. L.A. argued that those risks could be addressed by training just as the clinic provides. Convincing commissioners and lead provider remained difficult until a survey was co-produced and rolled out to people with HIV directly to help understand needs and preferences and build a closer relationship between service users and the clinic. As a result of their perseverance, most members of Our Area developed and brushed up their skills and took up related projects, leaving the legacy of an interactive website.

Picking up challenges from service users constructively

This paper referred to two premises at the beginning about co-production as a mutual, sensitive and multifaceted process containing informal and formal steps. Firstly, most of the (thousands) opportunities behind people expressing ways forward and taking leadership go unnoticed. Secondly, even if noticed, people's expressions are easily dismissed. This is because these expressions (despite substance delivered with great perseverance) do not lend themselves easily to the system's world of 'projects' let alone sustainable change in the form of contracts and rights. This is not an unresolvable dilemma.

One such expression is that of the group of young people with learning disabilities wanting to go swimming on their own terms. Services rejected this request with a stereotypical range of reasonable responses, heavily borrowing from the safeguarding agenda. The desire for swimming against set policies by the young people meant so much more than just jumping in water and having fun, for example self-confidence, independent living and the drive to achieve something by and for themselves. There is a direct underlying risk to swimming but this can be mitigated by ensuring a sufficient number of trained support staff is at hand which could simply be written into provider contracts – any holiday trip provider or zip-wire firm needs to have such insurance in place to make sure an activity can start. All this seemed completely irrelevant for the services despite and against the great emphasis on personalisation, co-production and outcomes in the local learning disabilities strategy.

This is a prime example of a challenge to a wasteful service machinery which often passively observes people's deteriorating needs rather than

helping them build up their sense of achievement and fulfilment. This requires frank and open-ended conversations between people and commissioners translating decisions into formal processes. Swimming as a right to a positive risk could be written into contracts, insurances and support arrangements under pooled budgets[6] for example.

Norming

Co-production can be enhanced by putting in place levers to help people and systems turn toward shared goals and lasting, formal improvements.

User-driven commissioning – reconciling individual with organisational needs and formal with informal approaches

A systematic approach that is flexible but still has some teeth is required to firstly gather fully people's experiences, needs and aspirations and secondly ensure that what people say will help improve services and take all closer to their health and well-being outcomes and life goals.

The process should contain an inwards phase for people to explore what is and also – crucially – imagine what could be. An outwards phase would support people to articulate their distinct sets of experiences and desired outcomes, help translate them into the system (across the cycle of commissioning) and make robust contributions to overseeing the actual co-delivery of any contract at stake, including peer support.

To this end, we developed some design principles and milestones for the undertaking of user-driven commissioning. For example, at the start there should be a clear and upfront commitment from the system to the people, eg to a 20-40% stake for a Lived Experience Team in deciding on the winning bidder in an upcoming procurement. This can trigger multiple practical and legal questions and challenges which are all surmountable if there is a shared will amongst people and system.

The 'inwards' phase starts with games for team-building so peers (without system representatives but with their own facilitation if required) over time start to feel free to open up, share and explore life stories. People then go on after a number of further sessions to map

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[6] A step guide on pooling personal budgets is available from RUILS
http://www.ruils.co.uk/services/pooling-budgets/

out risk and protective factors to feeling good, including about themselves e.g. What makes me feel better – with and irrespective of my condition? What are my life goals, and how close have I come to those?

The tools support people to explore current services and support – what roles do I want them to play in my life and support arrangement? This stage prompts people to take into account the wider local context and build on what peers have fed back in the past and other relevant information e.g. Joint Strategic Needs Assessments (JSNAs). This enables people to set out a free vision of what an ideal landscape of services and support looks like and the roles of all the different players within it, including completely new services.

Depending on the agreed purpose of any particular project, the team will then go through dedicated training in commissioning before facing 'outwards' to achieve robust and long-term impact, via (for example):

1. co-procurement (co-producing a service specification and Invitation to Tender (ITT) questions and scoring tenders),
2. articulating experience and outcome measures (turning indicators from above questions into metrics for contract monitoring) or
3. pooling personal budgets between people and between health and social care bringing together people with specific support needs in a defined local are (as precursors to peer-led commissioning organisations and capitated budgets)

There has only been one local authority embarking on this journey as part of the study despite a substantial number of system players we had invited. People in this local area with experience of the service concerned were recruited. They felt empowered by the given structure of milestones and design principles and built a strong Lived Experience Team meeting regularly with an independent facilitator over more than one year. A team profile and a robust specification for the service were co-produced, containing the most relevant outcomes and deliverables. This was to kick-start the formal procurement exercise with an extensive timeline of formal stages such as the Bidders' Conference up to contract mobilisation all to be co-delivered. However, in the end, unforeseen legal barriers (constraints on the tenancy of the provider) stopped the process and the local authority then failed to stick to its informal commitments and see this through together with the Lived Experience Team.

Building on a workforce standard to become more sensitive to disabled staff's everyday experiences

The stakes for maintaining the status quo ('the way we do things here') are high, but the system can put in place incentives to question practices and even unleash a new drive to achieve improvements across the whole workforce. A potential vehicle for this is the new Workforce Disability Equality Standard (WDES) in the NHS which has been shaped and pushed through with the help of disabled staff in and outside of the NHS against some reservations from powerful professional groups. A massive organisation like the NHS needs to build such an intervention on existing mechanisms of data collection such as the Annual Staff Survey and Electronic Staff Record – which are too established to spark change as some may argue. However, on the back of this it has been possible to prompt organisations to also collect data on new areas such as the existence of and support for disabled staff groups in the various NHS organisations. Altogether, the WDES can act as strong springboard for improvements in the workforce and services if it is used to enable disabled staff directly to drive and deliver relevant actions. As with all new initiatives and user projects it is key to find and get in touch with peers which has been described under 'ambivalent actions' above. Such information should include key contacts and examples to help people bring to life ideas on improvements in disability equality and make sense of what they may mean for themselves at different points in their lives. For instance, the system could suggest and then agree with people a broad area in which satisfaction (say with the recruitment induction and exit experience) should improve (from 40% very happy to 70% very happy) in a set timescale. A set disabled staff network could then think through, set and oversee the specific actions needed to achieve these set goals together.

Part of this could be about introducing people-reported outcomes that are grounded in everyday working life situations – 'recognising lived experience in supporting patients with long-term conditions in the NHS. This helps bring about staff reassurance more effectively than any set Key Performance Indicators (KPIs) and traditional line management which often merely fortify the power and routines of the system.

Disability as an Asset – unleashing the power of lived experience in supporting patients as peers

With a sense of ownership, influence and control over disability equality in the workplace for themselves, some disabled staff are attracted to go further and contribute their lived experience to improve patient contact directly – as described before under 'Opening discourse on disability as an asset. For some this approach can mean breaking through a double-bind and regaining professional clout and pride as (and not despite of) being disabled. Peers in less relevant posts may wish to be re-deployed to have greater patient contact and be more effective than they thought they could ever be. For peer-modelling between disabled staff and patients see www.disabilityrightsuk.org/peer-modelling

There is potential for a complete overhaul of the approach to patients which requires a redesign of key aspects in patient pathways, eg about how a serious diagnosis may be conveyed to a patient by staff who had a similar diagnosis in the past. At the beginning there must be a clear commitment to a culture of 'lived experience informing everything we do here', and this can be established by various means and at various points of time. Information lends itself easily to such 'test beds' – what and how can staff with lived experience help shape every single leaflet, posters, videos and standard patient letters.

Moving towards patient contact, the disabled or lived experience staff group should co-produce (ideally with some patients) a set of staff-patient boundary guidelines and clarify in which care area the approach might be tried out first, eg mental health or (breast or prostate) cancer. It is important for the NHS organisation to invest in this process with substantial (released) time, an open mind, support, upfront commitments and the possibility of not reaching any of the desired outcomes. The working group needs to have a confidentiality agreement in place, be supported to build up full trust in each other to explore individual and collective stories of managing a long-term condition, including setbacks, support networks, what helped or hindered to feel good about themselves at key points (protective and risk factors), etc.. It will help to share some milestones of this journey in wider staff forums and community blogs but keep control over the time of the actual 'test launch'.

The boundary guidelines themselves would include aspects such as:

Sharing information about own personal experiences is a very personal and dynamic endeavour. There are two people in the encounter – the professional peer and the patient, and both need to interact flexibly with each other, eg by picking up on each other and opening or closing down a path proving to be undesirable for one or the other.

It needs to be made specific what kind of information can be shared and when. There needs to be support and guidance for supervisors and line managers in advising and supporting staff about sharing experiences. Processes need to be put in place to positively and effectively address challenges for individuals, teams, line managers - eg complaints, meeting people who know personal information in other contexts - as staff, volunteers etc..

Concluding considerations about 'balancing acts"

So, in conclusion, was there some success along the whole pathway from initial self-exploration of a group of disabled people amongst their own peers all the way up to truly co-producing and overseeing new services and support that matter? No, the mantra 'You said. We did (together).' has not materialised in that complete, overarching sense. The findings from this study are fragmented just as our widened approach with different starting and exit points. At the very least, this means we may have revealed a spectrum of disabling practices (barriers), ambivalent, dynamic interactions and some promising routes to direct impact (drivers).

Overall, we still see most providers awarded for unnecessary 'activity' and actual independent living 'outcomes' ignored – sometimes despite nearly perfect rhetoric by very well-trained system representatives. Many of us get too little of what we have asked for and too much of what we have not asked for, if the system does not fail us across whole life domains as confirmed by the report on the UNCRPD referred to at the beginning. It is clear that innovation and traction for real change both come from disabled people but systems and processes with all their infrastructure for the time being prevail: the ruling consensus often still is that care is provided TO the person instead of health and independent living improved together WITH the person. The NHS has introduced the

costly 'Patient Activation Measure' to measure progress in that direction – interestingly, our question to the corresponding team at NHS England about which tool may help activate staff for co-production sparked but confusion.

As part of the study we analysed some guides and models for co-production but realised that most appeared in real life checks too formulaic or static. In conclusion and summary, addressing a number of factors could help people to inform and oversee services so that services resonate better with how people live their lives, including skills of problem-solving, inclusive team operations and wider strategies:

1. Provide and seek facilitated space to look inwards and self-explore and also form terms and conditions for self-representation and impact – sometimes concurrently
2. Accessibility and co-production go hand in hand – not one comes after the other or can ever be 'ticked off' as completed
3. There is a requirement to be flexible when making improvement but seek to widen the scope of change (of a project) only so much that the system can (still) make specific, meaningful and effective upfront commitments to people, eg allocate a 40% stake in the decision on a winning bidder upfront to the Lived Experience Team
4. Provide and seek impact in defining outcomes ('what does good look like?') but also in finance and contracting models ('which outcomes does the provider need to achieve in order to be paid?')
5. Source and keep alive opportunities for co-delivery as well as in overseeing, mobilising and monitoring provider contracts

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