Working alongside people with lived experience (experts by experience)

Principles for ensuring respectful and fair co-working

A Community of Practice resource

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A commitment to fair and respectful working with ‘experts by experience’

Members of the Restraint Reduction Network are committed to working in ways that eliminate the use of coercive and restrictive practices, as well as reduce and minimise the use of any restrictive interventions including physical restraint.

Central to delivering restraint-free services is the optimisation of policies, working practices and training. A significant step towards developing sensitive, insightful, meaningful and ultimately human interventions is to work alongside people with lived experience or ‘experts-by-experience’, in both the development and implementation of such measures.

The Social Care Institute for Excellence in their 2013 ‘Knowledge review’ identified “User and Carer Knowledge” as one of the 5 knowledge types that could be drawn upon to improve practice. This ambition was summed up as follows: “Better Knowledge for Better Practice” (SCIE, 2013A p.2).

Some fantastic work and incredible value knowledge has been used to great effect in this co-operative space, but for too long there have been cursory, tokenistic and uncaring activities taking place under the banner of ‘joint working’ or ‘co-production’. Such engagements are inauthentic, unlikely to be effective and even harmful.

The Restraint Reduction Network Community of Practice (RRNCoP)

The Restraint Reduction Network Community of Practice (RRNCoP) represents a networking space populated by diverse collection of individuals and organisations who want to see work in this area done well. To that end a number of practitioners have contributed to the development of this charter.

The RRNCoP doesn’t claim that this is a definitive resource. In many ways it is still very much a work in progress. It does however represent a robust starting point that can be used to stimulate debate and planning as well as the development of true co-working.

Co-working: a public policy goal

Co working in all its forms ensures both recognition of public policy goals, and the practical value of infusing any initiative that follows on from this with an informed insider’s perspective. One that raises the resultant integrity of care and support as well as that of any crisis interventions.

In social care settings a significant driver is the Care Act 2014, which states: ‘Local authorities should, where possible, actively promote participation in providing interventions that are co-produced with individuals, families, friends, carers and the community. “Co-production” is when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered.’ (Dept. of Health, 2014A, SCIE, 2013B).

The Government’s mental health policy strategy - the Five Year Forward View for Mental Health – also calls for what it refers to as ‘co-production’, and for it to be integrated at every phase of the commissioning cycle. It contains an explicit statement to the effect that every
person with a mental health condition should be able to be confident that services have been designed in partnership with people with relevant lived experience, and that standards for care and support should be developed via co-production (Dept. of Health, 2016).

For the purposes of this document the focus is on a very specific facet of public policy, namely restraint reduction or the reduction/elimination of restrictive interventions and restrictive practices. This was first publicly stated in the ‘Positive and Proactive Care’ document (Dept. of Health, 2014B).

**Defining an ‘expert-by-experience’**

Various definitions exist of ‘expert by experience’ (EbE). These include:

- “An expert by experience is someone who has personal, lived experience of using health, mental health and/or social care services, or of caring for someone who uses those services.” (NHS Improvement, 2018)

- “Experts by experience are people who have personal experience of using, or caring for someone who uses, the health, mental health and/or social care services that we regulate” (CQC, 2017)

Within the context of the Restraint Reduction Network Training Standards a more expanded definition is used which recognises the importance particular types of experience, specifically that of exposure to restrictive interventions:

- “People with a lived experience of receiving services and experience of having restrictive interventions applied to them” (Restraint Reduction Network, 2019) - The term can also apply to families and carers

The RRNCop have developed an expanded definition which also distinguishes between experts by ‘direct’ and experts by ‘indirect’ experience:

- “An expert by (direct) experience is someone who has had direct experience of living with a particular diagnosis or status, and of receiving care, support and/or treatment as well as the potential exposure to restrictive interventions aimed minimising or managing those behaviours which may have been presented during periods of crisis or distress

- As a result of this lived experience they possess a unique insight and understanding that allows them to think, feel and act in ways that brings an ‘added value’ to whatever form of partnership working they are engaged in

- Partnership working designed to either dispel stigma, raise awareness or understanding, enhance or improve practice and/or reduce distress but ultimately decrease and ideally eliminate the future use of restrictive practices and/or restrictive interventions”
The intention with this definition was to create a description that is:

- **Active and future focused** (the person is determined by what they are doing now, not solely what happened to them in the past)
- **Goal orientated**, with its intrinsic restraint reduction related ambitions it establishes a defined purpose, something to achieve, and a form of progress that an organisation can find ways of measuring,
- **Embracing partnership working**, it recognises that relationships and human reciprocity which are fundamental to the human condition, are central to inclusivity and personal growth/change
- **Places an explicit value on the experience the person brings to the work** (in this sense the ‘expert’ is qualified by virtue of implicit/tacit knowledge they have acquired through experience - more below)

The foregoing definition centres on the individual with the direct diagnosis and/or experience of care and/or support. Those caring for and supporting experts by (direct) experience will have extremely valuable insights relevant to that specific role. In recognition of the differences a supplemental definition is provided:

- “An expert by (indirect) experience is someone who has had direct experience of caring for, supporting or living with an individual with direct experience of a particular diagnosis or status”

**Appointing an expert with the right experience**

Appointing the right EbE is key to the success of any project. Someone with experience of the mental health system might not be best placed to develop training for support workers working within a learning disability setting. Likewise, someone who hasn’t had direct exposure to restrictive interventions is unlikely to provide the same level of authentic insight as someone who has. Similarly, a carer or family worker would be able to provide a unique perspective on living with and supporting someone with a particular condition in a way that the person in receipt of the care support can’t.

To this end an informal ‘Schedule of Experience’ is offered. When commissioning projects, one should ask oneself exactly what type of experience is vital to the project goals?

Experience of an expert-by-direct-experience, who can share authentic experiences of:

- living with a specific diagnosis
- living through periods of crisis
- living with an index offence, or other potentially defining ‘label’ or perceived ‘risk factor’
- living with a particular status – e.g. voluntary patient, patient under section, prisoner, living in residential care, user of day services, student, carer etc
- being in receipt of specific treatments e.g. named medications
- experience of restrictive interventions, eg physical or chemical restraint (eg rapis tranquilisation)
• exposure to acts of discrimination
• exposure to acts of negligence
• participating in a MH tribunal
• trauma, providing the psych/emotional context for any of the foregoing experiences

Experience of an expert-by-indirect-experience, who can share authentic experiences of:

• using primary, secondary and tertiary strategies
• using restraint restrictive interventions on a family member
• supervising carers who are authorised to use restraint
• specifying or evaluating carer training packages
• dealing with behaviours of concern
• dealing with adverse incidents including poor or harmful restrictive interventions

As a result of these lived experiences individuals are likely to have richer insights and be more attuned to particular issues. They are likely to be more strongly positioned to:

• anticipate the potential impact of certain decisions i.e., actions and inactions
• apprehend the impact; ie ‘feel’ or have memories (including sense and emotional memories) of such impacts therefore have a deeper understanding
• have heightened empathy – recognise the emotional states of others
• have a heightened capacity to co-feel – to experience and share such emotional states
• recognise the implications of decisions: A is linked to B which has an effect on C
• understanding how an environment is read, felt and experienced by powerless individuals
• recognises the other side to a rule, practice or decision, ie The experience of ‘No’ or of a particular prohibition or restriction as being a disqualification or negation of personhood

**Defining the function of any co-working arrangement**

It is important to distinguish between work that is healing/helping in and of itself, and the additional benefits arising from the work that is undertaken. The difference between the ‘intrinsic (the sense of accomplishment, social responsibility and increased social capital accruing as a result of the participation) and the ‘instrumental’ (impact associated with the delivery of the co-produced service) (SCIE, 2013).

When a project (or role appointment) involves working alongside a person with lived experience is planned carefully, implemented skilfully and facilitated sensitively it can and should lead to personal as well as professional growth opportunities. One must however be cautious when a therapeutic dividend is posited as the sole outcome of joint working. In such circumstances, in extremis, a commissioning organisation might be satisfied that the work it is undertaking is facilitative in recovery, but the individual themselves can be left with the sense that whilst there is a recovery aspect to the work they are not necessarily moving forward in a personal and in particular professional sense; they don’t feel they are growing beyond the confines of their diagnosis. An altogether too common refrain is that
the person was not adequately recompensed or professionally rewarded (“It was just expected of volunteers”, “I was only given lunch money” and even “I had to spend my benefits to travel to the job, and didn’t get that money back”). Such experiences can be disempowering and even described as ones feeling like the system is continuing to exercise ‘power-over’ them. It is vital therefore to clarify what is on offer when engaging an EbE.

Different levels of co-working with people with lived experience

Co-working or working alongside (sometimes referred to as ‘collaboration’, ‘joint working’ or ‘working with’) people with the relevant lived experience is something that may operate on different ‘levels’, these include:

- **Consultation**: where people with lived experience is asked for their views on a particular topic. That information is gathered, and often used to great effect. This may include completing polls or surveys, being interviewed or part of a focus group.

- **Participation**: where people with lived experience are actively involved in shaping a particular outcome. Further to consultation, such individuals may be involved in influencing the decision making process itself; they might help to define a particular measure, or to help to implement it or measure its impact. This may include developing policies and procedures or delivering workshops or training. It may be assuming a defined role, such as a peer support worker.

- **Co-production**: where people with lived experience are situated within the work being undertaken in such a way that they make independent choices and take decisions that directly influence the project and/or its outcomes. Such work may include sitting on certification, selection or review panels, or assuming other defined roles within organisations such as the Restraint Reduction Network which involve independent working.

The varying focus of the work

Work may be extremely varied, but with the right expert with the right experience extremely valuable work can be completed. Work may involve:

- consultation on a particular issue e.g. the experience of rapid tranquilisation or long term segregation
- sharing of their personal narrative
- designing training sessions or courses
- delivering training sessions or courses
- service design or planning
- peer support work
- training evaluation
- service evaluation
- policy evaluation
In order that those experts with whom you are working can understand the required commitment (as well as the expectations that arise from the offer of work) it can be useful to define the time parameters of the work. Such projects may include:

- **Standalone commissions**: these are one-off pieces of work. Often the completion of some form of consultation or conversation which may take an hour, a morning or a day
- **Involvement in specified projects**: these are typically longer term projects, requiring multiple attendances or numerous interactions. For example, the work involved in reviewing and/or evaluating a particular piece of work
- **Defined and enduring job roles**: again longer term, but often with a more regular involvement. This may include a part-time or full-time role as a member of staff, or as a team member to whom BILD are able to offer regular work. Typically, such roles involve a job description and a discussion about employment status or the provision of a contract of employment

Moving forward and ensuring positive engagement: power with NOT power over

**Positive engagement** is the foundation of the productive and rewarding working relationships that the Restraint Reduction Network is keen to see develop and flourish. It is characterised by treating those brought in to work alongside other team members (whether on one-off projects, or on an ongoing basis) with unconditional respect. It involves getting to know someone and working with them in a way that makes them feel safe, supported and valued. The authentic collaboration that this brings will ensure conditions are conducive to work that will reveal insights that can only serve to enrich understanding, enhance the work being undertaken and ultimately support the desired change or improvement. The Restraint Reduction Network are committed to Power ‘With’, Not Power ‘Over’ (See Appendix 1: Definitions of Power:)

**Negative engagement** by contrast is typically characterised by superficial collaboration that is tokenistic, transactional, impersonal, or otherwise serving an agenda driven by someone with an ulterior motive or vested interests. When engaging an EbE (in particular experts-by-direct-experience) you are often talking about individuals who have faced difficulty, adversity, hostility and even abuse and/or violence. Their position to offer valuable insights and perspectives means that they can also be vulnerable and sensitive to power imbalances. There must be a real commitment to working with such individuals as equals, in a reciprocal fashion, designed to eliminate such power differentials, and ensure individuals feel they can commence work from a position where they can exercise their choice freely, and feel in personal control. To this end the P.O.S.T.E.R. principles of fair and respectful co-working have been produced.

The process of engagement has been widely examined, but Nowell et al (2017) provide a useful diagrammatic representation. The illustration in Figure 1 captures the themes and subthemes that they determined were central to the process of effective engagement. The visual definition they provide centres around the notion being “around the table” from where they extended the diagramming to include what individuals “brought” to the table
and how individuals “interacted” with one another. The circular movement of information between parties takes place within the context of flat power structures, and so is non-hierarchical and therefore embodies the notion of ‘power with’ in practice. (see Appendix 1: Definitions of Power).

Fig. 1: Components of engagement. (Nowell et al, 2017)

The P.O.W.E.R. principles are designed to support fair, respectful and successful co-working within the context of restraint reduction, by fostering such positive engagement.
The Principles of Fair, Respectful, and Successful Co-Working: P.O.W.E.R.

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<th>GET THE RIGHT</th>
<th>PEOPLE WITH THE RIGHT EXPERIENCE</th>
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<td>What every restraint reduction related project or job role requires is the right person, with the experience and insight engaged on the right terms. This moves you beyond tokenism to real, productive co-working. In order to get this right, the planning team needs to ask: What experience and insights are required to serve this project? (Refer to the ‘Schedule of Experience’, p.4 and the ‘Outcomes and Expectations’ – see next section) An expert by experience will be only one part of a larger team. The success of any restraint reduction project is likely determined by the qualities of all involved in the design, planning, organisation, implementation, review and revision stages.</td>
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<th>SET OUT CLEAR</th>
<th>OUTCOMES AND EXPECTATIONS FOR ALL INVOLVED</th>
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<td>Irrespective of the scale or scope of the project, or range of the role you need to be clear about what you are hoping to achieve.</td>
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<td>• What are the project goals? Such project goals can be exploratory, explanatory or emancipatory.</td>
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<td>• What function does the role serve, and what are the responsibilities?</td>
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<td>• What are the outcomes by which progress can be measured? are they tangible products such as a blog or journal article? A report or policy document? Particular training resources? Or perhaps a video or podcast?</td>
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<td>• Are they less tangible (but never the less measurable) outputs such as a peer support worker? an advocacy service? A crisis befriender? A new trainer? A panel member? A critical review of a report?</td>
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The Restraint Reduction Network provide a useful ‘Reducing Restrictive Practices Checklist’ which is a self-assessment tool to help organisations ensure that the use of coercive and restrictive practice is minimised and the misuse and abuse of restraint is prevented. This can offer a good starting point for restraint reduction work for those just setting out.

Strategic goals are important i.e. reductions in the use of restrictive interventions or improved support mechanisms, however it is also important that those involved are able to achieve and progress within themselves in a way that is meaningful to them.
• What are the **personal goals** for team members?

Discussing and developing such goals should form part of any engagement process.

Any offer of work should clearly state any **expectations**:  
• What is required in terms of input? Will it involve for example offering an opinion, sharing personal experiences, or undertaking a task against a particular set of criteria.  
• Is the individual expected to attend a certain location or will work be carried out remotely via phone or Skype?  
• What are the time commitments?

All offers of work, **working agreements or contracts** should be provided so that an informed commitment to participate can be taken. For individuals who have often had bad prior experiences it is vital to ensure that any work is characterised by clarity, consistency and as far as possible certainty.

As and when appropriate **consent** needs to be obtained it should be sought prior to work commencing, and after any work has been completed. It should also make abundantly clear in any working agreement that a person can withdraw themselves or their consent at any point in time. This is particularly relevant in respect of the sharing of personal narratives relating to exposure to restrictive interventions and/or other traumatising experiences.

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<th><strong>ENSURE INCLUSIVE</strong></th>
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<td>Often those who have been exposed to restrictive practices and restrictive interventions have had powerful experiences of being treated as ‘other’, or as ‘lesser’. It is therefore very important to ensure that there is <strong>parity in relations</strong> between themselves and others who they may be being employed to work alongside or commissioned to work with on a short term project.</td>
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<td>Every organisation is different and the extent to which certain policies and procedures can be extended may be dependent of employment status. The aim however is that everyone should feel like they are treated the same and not differently. Conversely others within the organisations, <strong>co-workers and project participants should be provided with the knowledge, skills and /or information they require to work safely, sensitively and effectively alongside individuals with lived experience</strong>. It is also good practice to nominate an appointed person who can be readily contacted and deal with any questions or concerns arising.</td>
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Appropriate reward or recompense should also have been clarified and agreed in advance (if there is a concern that the offer of financial reward may be detrimental to any benefits an individual might be receiving, the commissioning organisations should retain the ability to signpost guidance or support to determine the best way to proceed)

People are able to do their best when provides with the support they require.

Communications may be many and varied, and formally include recruitment adverts, project overviews, offers of work, job descriptions etc. Such communications may also be supplemented with informal communications in the form of conversations, email exchanges etc. All communication should be unambiguous, honest and accurate at all times. The message contained within should be coherent and consistent. It should never involve or include speculative assertions, or what could be construed as intentions or a promises. Communications should be recognised as having the power to build hopes and expectations. Inaccurate, misleading or disingenuous communication can lead to confusion and disappointment. As such it can be experienced as uncaring, dishonest, abusive or even punitive by individuals those who have experienced the negative aspects of power being wielded over them.

Communications should be provided in an accessible format. This may include written, large print, easy read, audio or braille. It might be via BSL or Makaton, or involve the use of an appointed supporter to interpret.

Reasonable adjustments may include practical arrangement required to facilitate engagement as well as emotional/psychological support in the event ‘things get too much’. It is vitally important that such arrangements are qualified and clarified before work commences. Emotional and psychological support may in practical terms involve a wellbeing check prior to the commencement of work, as well as at the end and after. A follow up check can be very important. There should also be clear ground rules, giving the person the power to stop, take time out or ask for support as and when required. Again commissioners of work must be sensitive to the power existent in such relationships. It should be made clear that “its OK to say no, to stop or even withdraw from a project. A perceived pressure to comply or please can be the legacy of exposure to coercive regimes, and therefore conditions that emulate that can be conceived of exerting power over someone and even be re-traumatising.

The sharing of personal experiences can be particularly powerful. Certainly within the training context the recipient’s view of exposure to restrictive practices and restrictive interventions can provide an insight that makes staff members realise the power they wield when imposing restrictions on
others. A consideration of the lived experiences of those being restrained is a key course content requirement of the new Restraint Reduction Network Training Standards. (See Appendix 2 - Wellness Action Planning)

The standards however also require that **any personal disclosures of adverse experiences are undertaken safely and sensitively**. It is vital that the person sharing feels like they make disclosures on their own terms and retain control of their personal narratives. In which case it is best practice to make it very clear before any work is undertaken whether or not there is an intention to share, distribute, make publicly available or monetise any ‘outputs’. Explicit consent should be obtained and reviewed. The working relationship must never be, or perceived by the person involved to be, exploitative in any way.

When engaging with individuals with lived experience commissioners should ensure that any engagement if enabling and nurturing of **personal and professional growth**. Further to the personal experiences that are central to the work in hand there are the additional life skills and work skills that are brought to bear. Everyone has different sets of skills, as well as different levels of confidence so any engagement should be sensitive to this, and where appropriate provide support and development structures. An individual who hasn’t shared their experiences before but wants to may benefit from some coaching on public speaking or presentation skills, another may require assistance with IT equipment or the use of particular equipment. In this sense work might be construed as having a recovery focus, although this isn’t the focus of the work organisations committed to including individuals with lived experience are often able to demonstrate their wider commitment to personal and professional growth by providing person-centred support in this area.

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<th>EVALUATION AND LEARNING OPPORTUNITIES</th>
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**By taking time to evaluation what has been happening you can acquire valuable learning.**

Evaluation can take place at the **project or role level**. Did it work? If not, why not? What can we do differently or better? What can be rolled out across other areas within the organisation?

It can also take place at **team level**, and at an **individual level** as well as at **support level**.

In order to measure progress and impact of these level you will need to set aside time to determine exactly what you will measure and how. You will need to gather evidence, analyse it and make use of what you have found out. You can then celebrate and build on successes as well as learn from what has not worked so well. In the event gaps or shortcomings are
identified they should be taken forward in some form of organisational, team or individual development plans

Don’t forget to share your findings with others, including other members of the Restraint Reduction Network Community of practice.

**ALWAYS ENSURE FUTURE ORIENTATED**

**REVISION OF PLANS AND REVIEW OF CO-WORKING OPPORTUNITIES**

Reducing restrictive practices and increasing quality of life is not a once and for all endeavour.

New patients come and go, new people come into contact with the organisation for the first time. There might be a change in the economy, a new piece of legislation, a merger, a new service or change in systems or staff can all impact on service delivery and the experiences of those receiving it. New behaviours can occur, and old habits can re-emerge. Therefore, restraint reduction work can never truly stop. Successes can be celebrated, and lessons learnt can be learnt from what has come to pass. However, organisations that have restraint reduction in their DNA will always be open to change and improvement.

The economic case for investing in restraint reduction is a strong one, and in time hopefully evidence can be used to increase budgets and expand the number of work streams at any one time.

Goals need to be reset, with even more ambitious outcomes agreed upon. **Success is good but continuing success is better.** For progress to be made respectful, fair and ultimately personally and professionally productive co-working will need to continue.
Looking forwards: your project and its future

Anyone involved in a project such as this charter is designed to support should consider the following:

- The **Key Barriers** to exploring co-working and/or co-production can include:
  - Uncertainty about what it actually is, what it means and how to implement it
  - Practical constraints such as concerns over such as time and cost implications
  - Genuine concerns around the people’s welfare, as well the potential complications relating to any benefits/support received by the expert by experience
  - Resistance to change more generally to restraint reduction within the organisation, which may find a focus on co-working, often evidenced in resistant cliques and cultural inertia.
  - Counter demands within the organisation relating to core service provision

- Progress is however possible. Skills for Care (2018)* have identified several **Key Enablers or Facilitators** that helped their projects get off the ground, which included:
  - The presence of intellectually and operationally ‘fertile ground’ - an existing culture of involvement and respect for the views of people with lived experience
  - Inspirational leaders and managers that were prepared to ‘give it a try’
  - Staff disposed to an ethic of care or relationally which allows them to build strong and mutually beneficial working partnerships
  - Having commissioners and other strategic colleagues on board.

- Those things that can serve as **Grow Factors** can include:
  - Having structures and processes in place to sustain ongoing work, such as training and support
  - The recognition that people with lived experience might need extra support or reasonable adjustments at times, and putting systems in place to ensure that happens
  - A constructive feedback loop, including responding to challenges and concerns
  - A culture of honesty and transparency
  - Being able to demonstrate the benefits of co-production
  - A recognition that conflict is part of the process, and should be seen as a part of the process of change

*The 2018 Skills for Care document covers Co-Production in mental health. Whilst its context is very specific, many of the observations made are universally applicable and extremely helpful. See Appendix 3 for ‘Useful Resources’ and ‘References’*
Appendix 1: definitions of power

Power can be expressed in both positive and negative ways. It is its negative expression that gives the greatest cause for concern, whilst its positive manifestation it can be enabling at both individual and group level leading to actions supportive of growth, change and improvement. VeneKlasen and Miller (2002) describe four ‘expressions of power’ which provide useful distinctions:

Power over (-)

Probably the most commonly recognised form of power. It has a whole host negative associations for people within the context of restrictive interventions and restrictive practices in particular: invalidation, the restriction of liberty and freedoms, coercion and enforced compliance including the overzealous use of force. All of which can be harmful; psychologically, emotionally and physically injurious. The exercise of ‘power over’ an ‘other’ typically involves denying power to that person or collection of individuals and preventing them from gaining it.

Power with (+)

Power at the level of the willingly constituted partnerships or coalitions. ‘Power with’ has to do with forging respectful and reciprocal relationships, finding common ground or focusing on shared goals and engaging in collective creativity or productivity. Co-production takes place within such groups where power is equally and fairly distributed. The whole can be very much bigger than the sum of the constituent parts.

Power to (+)

Power at the level of the individual within a shared world. Here it is used to uphold personal rights and to respectfully explore and expand their social space, to meet their needs and exert their influence. The ‘Power to’ refers to the unique potential of every person to take control of, and shape his or her life and world. When based on mutual support, it opens up the possibilities of joint action, or ‘power with’.

Power within (+)

Fundamental power at the level of the personal individual. ‘Power within’ has to do with a person’s sense of self-worth, self-belief and self-knowledge. The ‘Power within’ is the capacity to imagine and have hope; it affirms the common human search for dignity and fulfilment.

The ‘power-over’ is used to disrupt the ‘power with’ to disqualify the ‘power to’ and ultimately deny the ‘power within’
Appendix 2: wellness action planning

A Wellness Action Plan (WAP) can help individuals to actively support their own mental health by reflecting on the causes of stress and poor mental health, and by taking ownership of practical steps to help address these triggers. It is an empowered rather than imposed support process.

According to MIND a Wellness Action Plan (WAP) should cover:

- actions and behaviours that support the employee’s mental wellbeing
- symptoms, early warning signs and triggers for poor mental health or stress
- potential impact of poor mental health or a mental health problem on their performance
- the support they need from their line manager
- positive steps for the individual to take if they are experiencing stress or poor mental health
- an agreed time to review the support measures to see if they’re working.

MIND have produced a ‘Guide to Wellness Action Plans (WAPs)’ which can be downloaded from the MIND website here: [https://www.mind.org.uk/media/1593680/guide-to-waps.pdf](https://www.mind.org.uk/media/1593680/guide-to-waps.pdf)
Appendix 3: useful resources

Joseph Rowntree Foundation

Service User Research Enterprise (SURE)
https://www.kcl.ac.uk/ioppn/depts/hspr/research/ciemh/sure

Strategies for Living at the Mental Health Foundation

The Sainsbury Centre for Mental Health

The Tizard Centre
https://research.kent.ac.uk/tizard/projects/

University of Hertfordshire
http://www.intellectualdisability.info/changing-values/articles/user-involvement

INVOLVE
INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research.

There are more researchers and research commissioners working alongside the public for the first time than ever before, and INVOLVE are committed to maximising that participation.

Read their statement about ‘Being Inclusive in Public Involvement in Health Research’

In conjunction with the National Institute for Health Research they have recently published ‘Briefing notes for researchers: public involvement in NHS, public health and social care research’ which contains ten briefing notes for researchers that expand on how to involve members of the public in research https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf

You can download their ‘Guidance on co-producing a research project’

You can visit their ‘User controlled research’ area, which covers research that is actively controlled, directed and managed by service users and their service user organisations. https://www.invo.org.uk/find-out-more/user-controlled-research/
References


Department of Health (2014A) Care and Support Statutory Guidance Issued under the Care Act 2014

Department of Health (2014B) Positive and Proactive Care: reducing the need for restrictive interventions

Department of Health (2016) The Five Year Forward View for Mental Health: A report from the mental health taskforce in England

INVOLVE (2018) Guidance on co-producing a research project


SCIE (2013A) Knowledge Review 3: Types and quality of knowledge in social care (Summary Document)


Thanks

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