## research in practice

# A brighter social care future: Co-producing the evidence to make five key changes

Leading the lives we want to live



### Use the social model of disability

### What this means

The Leading The Lives We Want To Live group draws inspiration from the social model of disability. This is a model developed by disabled people themselves, and states that people do not 'have disabilities'. They have impairments, and are disabled **by barriers in society**. Barriers can include the physical environment, people's attitudes, communication, how organisations and systems are run, and discrimination. If society was truly inclusive, these barriers would not exist - disability is caused by society's unwillingness to meet the needs of people with impairments.

It is not only the model itself that's important. It is the way it was developed, through the activism of disabled people. There is power and solidarity in sharing stories, experiences and knowledge between and beyond ourselves. This peer support doesn't have to be official, it can spring up whenever people get together.

If there is a key foundation that professionals need to have when supporting disabled people to live the lives they want to live, it is to understand, promote, and explicitly support the social model of disability.



(Illustration reproduced with the kind permission of Inclusion London)

"We need to talk about an acceptable quality of life, and this shouldn't just be decided by professionals."

### The research

Fenney et al. (2022), in research conducted for the King's Fund and Disability Rights UK, found that people often experience the 'medical model' of disability in both health and social care - where professionals would start from how to 'fix' a condition, or having a conversation about how people could adapt themselves to fit in better with their environment.

The people who were part of this study connected the medical model with a poor experience of care, and contrasted this with more positive experiences that started with feeling seen as a 'whole person'. Personalisation, and direct payments or personal budgets, can also promote the social model of disability, and help workers move from theoretical knowledge about the model to its use in practice (Glasby, 2012). However, it's important that there is proper information and support for this (see the section 'Communication and Confidence').

The social model of disability can sometimes be (wrongly) assumed to apply only, or mainly, to younger physically disabled people (Kattari et al., 2017), with older people more likely to be seen in the light of the medical model of disability. However, as the Mental Health Foundation (2015) found, using the social model of disability in dementia can support the agency of a person with the condition. The model also helps reframe dementia away from something seen as an exclusive and inevitable condition of older age – and, as a rights-based model, affirms people's rights to high-quality services.

The Leading the Lives We Want to Live group were also inspired by Simon Duffy's Keys To Citizenship model:



(Duffy, 2003)

Although originally developed in the context of people with learning difficulties, these are solid principles for living well and supporting one another. Thinking about citizenship can aid joined-up thinking, because it illustrates the links between relationships and structural aspects in society, while acknowledging the barriers people may face in claiming their citizenship rights (MacIntyre et al., 2022).

The role of peer support, and peer advocacy, can have a powerful impact on people's lives. Power et al. (2016), whose co-produced research concentrated on people with a learning disability, found peer advocacy could help people problem-solve, make friends, informally learn and share knowledge and skills. In the particular context of austerity in the UK, where services have been cut, peer support was one way of partially filling the gap of retreating day and community facilities (Power et al., 2016). Hyslop et al. (2020) also found high value in peer networks for people with personal budgets – disabled people sharing knowledge and stories about personal budgets helped to build people's confidence at each stage of obtaining and managing a personal budget.

### What you can do

**If you are in direct practice:** Do not wait to be trained in the social model of disability. Find out about it for yourself! Watch Jenny talk about the social model and go to the further information section below and learn about it. Speak to the people you work with, both those with care and support needs and other professionals, about its importance. What does it mean to people?

Think about the role of peer support and peer advocacy in your local area. Are there local groups you can connect people up with? How can you support bringing people together, so they may share their stories and knowledge without the power dynamics of non-disabled professionals being present?

If you are a senior manager: The Leading The Lives We Want To Live group suggested a wide and sustained campaign to promote the social model of disability – posters in buildings, reminders in letters, training delivered by disabled people on what this means (and how to apply it).

How can you, as an organisation, do this? How will you promote knowledge about the social model of disability – in its widest sense, including older people? Are you confident there is a shared understanding of the model, and how it should underpin work with people with care and support needs? And who judges this – is it the organisation itself, or disabled people?

A good place to start is by firming up links with local disability rights groups and considering, together, how you can work in close partnership. There may be work to do in auditing your organisation's understanding of the social model of disability; there may be training to be delivered; there may be changes to service delivery.

The first step is identifying any disabling factors at an organisational level and working on ways to remove these so that you can grow your organisation into an ally to disabled people, through both words and actions.

### **Further information**



### Read

Disability Rights UK has an introduction to the Social Model of Disability.

The Greater Manchester Coalition of Disabled People has published *A Brief History of Disabled People's Self-Organisation*.



### Watch

There are several accessible videos made by disabled people explaining what the social model of disability is and why it's important. Disability Wales offer a short, clear explanation from Natasha, a Deaf person (Natasha also talks about the cultural and linguistic models of Deafness in the video). The National Disability Arts Collection and Archive has created an animation explaining the meaning and history of the model. SCIE's co-production steering group created a film on the social model of disability for Co-production Week in 2020. Finally, Disability London has a BSL explainer of the model.



### **Engage**

Social Care Future publishes regular blogs by and for disabled people and their allies.



### **Explore**

The People's History Museum in Manchester has an exhibition, *Nothing About Us Without Us*, that explores disabled people's activism – past, present, and future. Even if you can't get to the museum itself, the website hosts films, guides, and a visual story about the exhibition.

### Systems and their barriers

### What this means

Unfortunately, there are current barriers within the health and social care systems. These barriers disempower people and get in the way of people 'leading the lives we want to live'. Although it is technically separate, the welfare benefits system has become more restrictive and also has many barriers – this is important, not only in itself, but because it can affect eligibility elsewhere.

Some of these barriers seem directly caused by lack of resources, for instance by not paying people for co-production. Some are about how organisations have evolved, with bureaucracy and fragmentation creating barriers – such as people being asked to continually repeat their stories – where none may have been intended. Disagreements about money between health and social care can directly affect people, because these lead to delays and make people feel they are being bounced between different panels and organisations.

An outcomes approach means just that - that outcomes are the focus, not for systems to get tangled up in talking to each other.

"No-one means to put a barrier in your way, but it happens nonetheless."

#### The research

Person-centred practice is about focusing on a person's **outcomes** - which is about the impact support or services have on a person's life (Glendinning et al., 2006), rather than the means by which they're delivered. True outcomes-focused practice moves towards greater integration of services, as it should matter less who pays for the services than the outcomes it delivers (Kelly et al., 2020). These issues are also explored in the More Resources, Better Used key change section, particularly when thinking about waste and efficiency, and transitions.

However, in a study looking at how the success (or otherwise) of health/social care was measured, Kelly et al. (2020) found '...despite the drive for integration to provide person-centred and tailored care to benefit the patient, the measurement of patient and carer outcomes were identified slightly less frequently than system outcomes or process measures.' This indicates that who defines or evaluates a successful integration is not always the people who will feel its impact (Kelly et al., 2020).

Increased co-production is as important when thinking about how to tackle issues arising through poor integration, as it is when identifying and addressing barriers. There's also more information about this in the *More Resources*, *Better Used* key change section – particularly within the passage on Accountability.

The Disability Benefits Consortium (2019) has calculated that disabled people lost, on average, £1200 per year, every year, in the years since 2008. The more impairments a person has, the more money they lost. The lost money was due to several cuts working in tandem - including benefit freezes, benefit caps, removal of disability premiums, and the introduction of universal credit. The experiences of assessment for work capability and for Personal Independence Payment were sometimes highly stressful, and had an adverse impact on wellbeing regardless of whether the assessment resulted in the required level of support (Hudson-Sharp et al., 2018).

In addition, White (2016) found that welfare benefits changes had a negative effect on the social care workforce, too - increasing demand for services generally, and specifically on the proportion of professional time spent reassuring people affected by welfare benefits changes, and guiding them through the system. Workers were emotionally distressed, frustrated and angry at how the lives of people they worked with were affected (White, 2016).

### What you can do

If you are in direct practice: The research suggests that navigating the welfare benefits system, and health and social care systems, is often difficult for people (see, also, the section on Confidence and Communication). It is really important for you to be an ally in doing this, while acknowledging your own possible feelings of frustration and distress. (On that final point, you may find it helpful to think about issues around emotional resilience for adult social care professionals, and the support you should be able to draw on from your own organisation.)

Local advice and advocacy services may also be able to offer direct help to people, but much of the signposting and emotional support work will likely still rest with you. You may be the only person who someone can contact directly. What support do you need in helping people? What extra knowledge would be helpful? It may be useful to analyse, as a team, what system-related queries come up repeatedly and devise a team strategy for helping people through them.

**If you are a senior leader:** Pro-active work to join up health and social care is also covered within More Resources, Better Used [links]. A key, evidence-based way in which you can contribute to joining up services, so people with care and support needs experience fewer fragmented and delayed responses, is to practice **systems leadership** alongside co-production.

For an example of systems leadership, consider Local Area Co-ordination in Thurrock. Senior managers from adult social care deliberately and proactively engaged with other senior leaders in housing, mental health, fire and rescue, public health, and the police. This led to the creation of Local Area Co-ordinators (LACs). LACs don't provide a formal health or social care service – instead, they ask the question "What would make a good life for you?"

You can read more about Thurrock's LACs here, with examples of help offered.

### **Further information**



**Explore** 

Citizens Advice has comprehensive information on the full range of welfare benefits in the UK.

There is a suite of resources on outcomes-focused practice from Research in Practice, including dedicated resources for managers.



Tool

MyCommunity has a tool designed to help with mapping assets in your local area.



Read

A briefing on Systems leadership - enhancing the role of social care from Research in Practice.

### **Avoiding stereotyping**

### What this means

One member of the Leading The Lives We Want To Live group remembered a phrase a worker had used when talking of her daughter: "She doesn't fit the model."

Avoiding stereotyping is about investing time, interest and reflection when getting to know people, otherwise stereotypes and assumptions can easily perpetuate or develop. While this is a systems issue – in making sure worker caseloads allow scope for this relationship-based work – it's also the responsibility of individual workers to reflect on and address stereotyping within themselves, and challenge it where there they find it in the course of their work. This is linked to wider work in the social care field to support equity, diversity and inclusion.

One set of assumptions that was discussed in the group at length were those made about family care, from assuming that family members would always continue to provide care, to the assumption that parents or family carers are the people best placed to provide care. "That's not an independent or equal life," commented one group member. "That's a negotiated life."

"We are all individuals; we all have different views and experiences. We need to be asked what kind of life we would like to live."

### The research

Stereotyping can be defined as '...generalisations about the personal attributes or characteristics of a group of people' and many 'have a long history and were created as a result of specific economic, political or social circumstances' (Rosenthal & Overstreet, 2016). Stereotyping can lead to negative beliefs (prejudices) and discriminatory behaviour. Stereotyping can also operate in an **intersectional** way – where a person's various social and political identities can combine to create a different stereotype. For example, a study by Petsko and Bodenhausen (2019) found that Black and ethnically minoritised gay men were seen as 'less prototypical' of their race, and assumed to be more affluent or of a higher socio-economic status than other men who shared their racial identity.

Ageism (discrimination arising from a negative stereotype of ageing) can affect whether older patients receive treatment, as well as the duration, frequency and appropriateness of that treatment (Chang et al., 2020). Hagan and Campbell (2021) found that media stereotypes of people with dementia are often internalised by those who live with dementia, and believe themselves useless, with these stereotypes increasing anxiety and depression.

This may also be an issue for people with learning disabilities. The form of bias known as 'diagnostic overshadowing' is where a health or social care professional makes the assumption that the behaviour of a person with a learning disability is solely due to that learning disability, without exploring other factors (Hallyburton, 2022).

A 2022 report, which surveyed both adult and children's social workers, found that 31% of workers had witnessed racism being directed at adults or families who draw on social care by colleagues and managers more than once (Gurau & Bacchoo, 2022). In a study looking at the physical and mental health impacts of racism in the UK, adults who experience racism experience greater psychological distress, poorer mental functioning, poorer physical functioning, and lower life satisfaction (Hackett et al., 2020).

Six assumptions that health and social care services can commonly make about family carers were identified by Williams et al. (2015). They are:

- 1. Caregivers will be there, willing and able to step up. That for moral and ethical reasons, or because there are no alternatives, carers will take on an increasing responsibility for care.
- 2. This is about older people. This erases the experiences of disabled working-age adults and those who care for them.
- 3. Money alone will do the job. That providing more cash by itself enhances choice and reduces stress for carers. Instead, carers require an individualised mix of supports as well as adequate money.
- 4. You can wait and see. That services can leave it to crisis point that carers will 'soldier on' until then. Instead, early intervention could do much to ease carers' stress, and lead to better planned support. Carers who don't get early support are more likely to support hospital or care home placement for the person they care for.
- 5. Leave it to the frontline professionals. Views about what carers can and can't (and should, or shouldn't) do can vary widely between different professionals. Leaving decisions about a carer's eligibility for support only with frontline professionals risks inconsistency and discrimination.
- **6.** Address carers separately. The belief that a carer's needs are distinct from those of the person they care for. While it's important to treat carers as individuals, taking a family-based, holistic approach to the situation is more likely to provide a more accurate picture of how care and support operates in the home.

There is also material about addressing stereotyping of carers within the More Resources, Better Used key change section, when thinking about recognising and rewarding family and informal carers fairly.

One of the most effective ways for practitioners to cut through possible issues of stereotyping is by utilising professional curiosity. Professional curiosity involves questioning and challenging the information practitioners receive, and not only identifying concerns but making connections to better understand someone's situation (Thacker et al., 2020). Understanding and taking a mentalising approach – where practitioners reflect on the complex interplay of factors that may underpin people's behaviour – is also important in addressing stereotyping (Raynes et al., 2016).

### What you can do

**For everyone:** It is of critical importance that you think about how stereotyping, prejudice and discrimination can affect decision-making. For example, consider the six assumptions about carers, above. Do you see any of these operating, perhaps implicitly, in the work you do or within the processes of the organisation?

Everyone has different experiences of power, privilege, discrimination and identity. Thinking about the research messages above, and using the exercises contained in the **Social GGRRAAACCEEESSS tool**, can help you reflect, and then plan, for action.

### **Further information**



Watch

A brief introduction to the Social GGRRAAACCEEESSS from Karen Partridge, Systemic Development Lead at the Tavistock and Portman NHS Trust.



Use

There are many other resources on the **Supervisor Development Programme** website that are aimed at an adults' social care audience, and which support developing equity, diversity and inclusion.



Read

Research in Practice has published several blogs on anti-racist and anti-discriminatory practice in adult social care. These include thinking about the impact of racism and promoting anti-racist practice.

Research in Practice has frontline tools on *Professional curiosity* and *Taking a mentalising approach*.

### Acknowledge and value the positives

### What this means

Please seek out and share the positives! When accessible, inclusive, thoughtful practice is widely acknowledged and applied, this will encourage more of it to happen.

Not everything can be measured by saving, or the efficient use of, money. Thinking about the 'social return on investment' - capturing benefits not easily mentioned in financial terms - is important to provide a true picture of the positives in people's lives.

"Good care saves lives. This is important to remember."

### The research

In the public sector, the benefits of investment - such as in a greater number of social workers, or in well-maintained and accessible green spaces - do not always have a clear financial 'return' on investment. It's summed up in a quote often mis-attributed to Albert Einstein (but probably originating from sociologist William Bruce Cameron): 'Not everything that counts can be counted, and not everything that can be counted, counts' (Cullis, 2017).

The belief that public and voluntary sector investment is not always easily measured in financial terms has given rise to the idea of Social Return on Investment (SROI). This model gives a methodology for calculating value, using financial proxies, which is usually expressed through a ratio (Arvidson et al., 2013). So, for example, an SROI of 3:1 expresses that for every pound invested, three pounds' worth of social benefits are generated. There is a guide to Social Return on Investment, which can assist with calculating SROIs.

As well as a methodology, SROI has seven principles:

- 1. Involve stakeholders.
- 2. Understand what changes.
- 3. Value the things that matter.
- 4. Only include what is material.
- 5. Do not over-claim.
- 6. Be transparent.
- 7. Verify the result.

(Nicholls et al., 2012)

Arvidson et al. (2015) found positives, challenges, and drawbacks with using SROI:

#### **Positives**

- > It can generate positive headlines, as it is easily understood by many people.
- > It can close the 'credibility gap' between private sector organisations and those in the public and voluntary sectors.
- > It explicitly acknowledges that the work of public and voluntary sectors takes place within a complex web of stakeholders, keeping people who draw on their services central to calculating value.
- > It links together the financial language of commissioners and funders with less tangible wellbeing outcomes.
- > The use of SROI can help direct resources towards their greatest impact.

#### Challenges

- > Some benefits remain very difficult to quantify and compare, such as rises in self-esteem or confidence.
- > It can be time-intensive and needs resources in itself to develop.
- > The question of who decides what should be measured needs to be carefully considered, as this is a judgement rather than an objective reality.
- > It can intensify pressure on public and voluntary sector organisations to prove 'value for money', when not everything can be measured in those terms.

This suggests that, while SROI can be a useful model, it's important that it doesn't detract from an outcomes focus, or risk seeing benefits only in financial terms. It's helpful to think of it **alongside** outcomes-focused and strengths-based working. Strengths-based working is a model of practice that values people and the positive qualities of workers. It focuses on the things that are important to people – without dismissing or minimising need. It can be contrasted with the theme explored within the Painting The Worst Picture key change.

Just like SROI, strengths-based working has a series of principles at its heart:

- 1. People can learn, grow and change.
- 2. The focus is on individual strengths rather than deficits.
- 3. The community is viewed as an oasis of resources.
- 4. The individual is the director of the helping process.
- 5. The worker-person relationship is primary and essential.
- 6. The primary setting for the work is the community.

(Adapted from Chamberlain in Ford, 2019)

Strengths-based practice has historically been seen as an investment from the social care sector that has proved difficult to measure accurately. It has been argued that there is a lack of research evaluating its effectiveness (Ford, 2019), and is an area of social care where practice is ahead of research (McLean et al., 2017).

However, Best et al. (2021), examining strengths-based models and their use in prisons, suggested some concrete things that **could** be measured as evidence of effectiveness of strength-based practice, which looked beyond 'starburst' (where the benefit is so short-lived that it had no lasting impact on wellbeing). These are:

- > Self-report of wellbeing.
- > Reduced indicators of harm and poor outcomes.
- > Staff measures like retention and absenteeism.
- > External inspection.

Best et al. (2021) conclude by saying '...if strengths-based approaches are to be seen as more than simply froth or as a pleasant distraction of prison life, then they need to have a genuine impact on the things that matter to the wellbeing of the prison'.

### What you can do

If you are a senior manager or a commissioner: In the evidence, above, there are principles both for social return on investment and on strengths-based working. What are the similarities between them, and what are the differences? You might also think about the common implicit thread of co-production - even though it's not explicitly stated, both models need people to define and benchmark what is of value to them.

Think about the phrase used above, about seeing strength-based practice as more than 'froth and a pleasant distraction'. It's clear that the Leading The Lives We Want To Live group value strengths-based working that celebrates the positives. How might you measure, celebrate, and share the benefits of strengths-based working with your local community, your staff, and beyond?

If you are in direct practice and/or a team leader: The Leading The Lives We Want To Live group said that you should be able to proudly say "This is what I did today, and I'm so proud of it. What I did really made a difference in someone's life."

It's everyone's responsibility to recognise when they've done a good job - a team manager, the wider organisation, people with care and support needs - and your own responsibility. How can you celebrate positive change in your team? How can you cultivate pride? How can you extend kindness and recognise strengths?

The SWORD Emotional Resilience Tool suggests a simple behaviour change, which is that all workers put their 'strengths goggles' on. This is consciously adopting a mindset that identifies strengths as they happen. After you spot strengths in people, point out the strength that you observed, tell them the reason for your observation, and express your appreciation (Grant et. al, 2022).

### **Further information**



### Read

For more information on social return on investment, the SROI network has published a guide, which includes sections on establishing scope, mapping outcomes, evidencing outcomes, establishing impact, calculating the SROI, and reporting, using and embedding.

Research in Practice has a Leaders' Briefing on Co-production and strengths-based practice and a Strategic Briefing on Developing strengths-based working.



#### **Share**

This brief guide to strengths-based practice is an accessible and clear overview for people who draw on adult social care.

### Communication and confidence

### What this means

This is a big topic, and ranges from people who do not communicate verbally and assumptions being made about how they wish to live their lives, to confidence in navigating the health and social care systems.

If getting what you are entitled to depends on communicating in one particular way (such as over the phone or via the internet), or is dependent on knowledge of jargon or legal processes, that system is **not equitable** and **not accesible**. Time, a range of communication methods, and patience, are all key in addressing this.

"The difficulty is that services often do not allow people time to communicate in the way that they need to."

### The research

Just as in the sections in the Sharing Power As Equals key change (Power is subtle and unspoken, and Simplify!), and Living In The Place We Call Home [the importance of accurate and reliable information], communication – and organisations paying attention to the importance of this - was deemed vital by the Leading The Lives We Want To Live group.

To illustrate how fundamental individual confidence and the ability to self-advocate (or to have someone to advocate on your behalf) has become to navigating social care, it's helpful to look at access to personal budgets and direct payments in social care. Hyslop et al. (2020) identified a 'sympathetic cultural space' as being important for the take-up of personal budgets among people who were entitled to them, which could include both professional and peer support, plus belief in concepts such as the social model of disability and the right to independent living. Confidence and assisted communication are consistent themes across the literature on the take-up and successful use of personal budgets (Hyslop et al., 2020).

Minic and Smith (2022) looked at the Scottish context of **self-directed support** (a system enshrined in law in Scotland, where people have a legal right to choose from **four options for their social care**, including to take direct payments). Among the findings were:

- > People often needed more than one conversation to work out the best approach for their support.
- > There was value in broadening conversations to family members and other professionals, to gain different perspectives.
- > While the option of direct payments was considered the avenue for greatest choice and control, people felt underinformed about the bureaucracy and responsibilities involved.
- Information was not always provided in a range of languages.
- > 'Local authorities' overly prescriptive and inflexible approach to how self-directed support can be used was a common experience' (p.40).

(Minic & Smith, 2022)

Underpinning both of these pieces of research are two related ideas. The first is that access to self-directed support, and the choice and control it offered, needed clear and empowering communication. The second is that this clear and empowering communication, in itself, needed time, space, and accessibility to happen.

### What you can do

If you are in direct practice: The fundamental point made by the Leading The Lives We Want To live group (related to the theme on empathy and kindness) is that, if there is time for worker and person to get to know each other, they will be more likely to understand each other. This means that workers will truly understand what is important to people, why people want the things they do, and how their wellbeing will improve if they are able to do them.

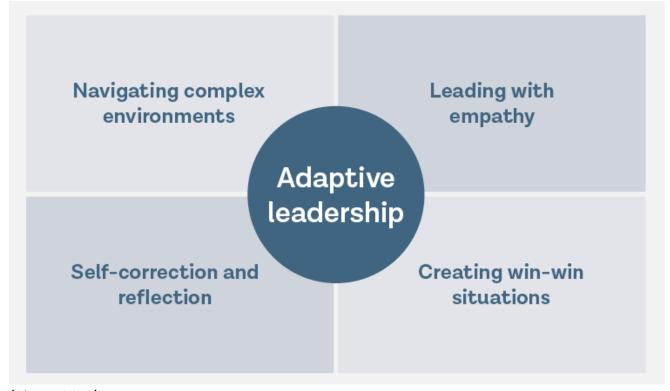
While the group realised that being in frontline practice could be complex and stressful, they urged a rethink in how time was apportioned. For example, if people did not understand something, they were more likely to either give up on it (and thus risk their needs worsening, or independence being compromised), or contact the worker again for help, thereby using up more of everyone's time.

While there isn't a magic bullet to achieving more time in a social care world of constricted resources, you may reflect here on the support you provide for communication and understanding.

- Do you know where people can access advocacy, and do you regularly share this?
- > Can you follow up complex conversations with people, to check their understanding and ask if they need any additional help?
- > Are you clear in your own legal literacy and confident you can support people to ensure their rights are upheld?
- > Do you feel comfortable raising issues of time management in your team?

If the answer to one or more of these is 'no', think about raising these issues with your supervisor, working together to explore how you can develop these capabilities in your practice.

If you are a supervisor: In the role of supervisor, you have moved 'from the dancefloor to the balcony'. This means that you can practice 'adaptive leadership', which is a way of working which can be particularly effective where there are no easy solutions. There are four dimensions adaptive leaders keep in mind:



(Shaw, 2019)

You can use this model when thinking about the difficult question posed by this theme - how can you foster more supportive communication, which requires time and space, in a sector which is often short of both of these? For instance:

### Navigating complex environments

How can you support your supervisees to reflect on this challenge, and plan for the future? For example, consider the tension between the short-term need for work to be completed, with the longer-term goal of improved wellbeing. Who else might need to be involved in these conversations?

### Leading with empathy

How does the lack of time to spend with people affect your supervisees? And how do your supervisees think the lack of time affects people with care and support needs?

### Self-correction and reflection

What can be tried to change this situation? Try to accept that your approaches to address this might fail – and be willing to make changes and corrections. How can you obtain meaningful feedback on any new approach from people with care and support needs, and then act on it?

### Creating win-win situations

Try to move away from a zero-sum approach (that if you allocate more time in one direction, something else must inevitably suffer). What would success look like for everyone in this situation? What steps can you take to achieve it?

### **Further information**



Watch

Skills for Care has a webinar on practical time management in social care.



Read

Research in Practice has a practice guide on Supporting practitioner wellbeing.

### The power of empathy and kindness

### What this means

"They can't take away kindness", commented one member of the Leading The Lives We Want To Live group. Another replied, "...even though they may try to." This exchange relates to the idea that, often, professionals want to be kind and empathetic but find their time and ability to do this squeezed.

However, the group also wanted to make it clear that kindness alone was not enough. It is not a substitute for professional, well-funded, care and support, and it should not be treated as such.

Valuing kindness and empathy alongside other worker qualities should be embedded in an organisation. People are asked to share their stories, but these stories can often involve frustration, anger, irritation and tears. Feeling safe to express these, and gaining understanding rather than feeling judged, involves trusting relationships. Encouraging workers to 'walk a mile in the shoes' of people who draw on social care, for example by bringing the experiences of people with care and support needs directly into training - while providing support for worker resilience - is a key way to develop (and value) kindness and empathy.

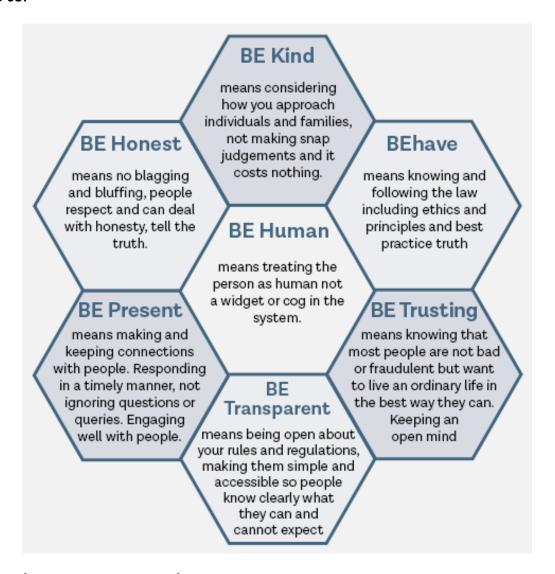
> "Workers might think differently if they could only visit the toilet three or four times a day!"

### The research

Across the UK, people who report high levels of life satisfaction are also more likely to report strong experiences of kindness in their communities (Wallace & Thurman, 2018). 63 % of people agree that, when others are kind, it has a positive impact on their mental health (Mental Health Foundation, 2020). However, experiencing kindness (or not) can reflect wider inequalities. Wallace and Thurman (2018) found that Black and ethnically minoritised people are less likely to report strong experiences of kindness in their area, and those from more privileged backgrounds experience more kindness in their communities.

The Be Human movement, formed by people and organisations connected to In Control, published a 2021 report that researched the effects of older and disabled people experiencing automation, unfeeling responses, bureaucracy and confusion from systems designed to support them - which might be considered as the opposites to kindness and empathy. The study grew from the coronavirus (COVID-19) pandemic, but also has resonance beyond it.

Arising from this project, citizens across the UK created seven principles for organisations to adhere to:



(Cockayne et al., 2021)

Another project, the Kindness Innovation Network, analysed the conditions needed in organisations in order to enable kindness. It found there were often unspoken barriers to kindness that organisations needed to consider in order to embed kindness:

- 1. Attitude to risk. If organisations were overly risk averse, they could create blanket and inflexible rules that overrode kind responses and created a lack of trust in human relationships to address challenges.
- 2. Impact of regulation and professional guidelines. A frequent finding was that workers felt that, in order to be kind, they had to break rules for instance, hugging people when they were not meant to, or giving out their personal phone number.
- 3. Reluctance to let go of performance management. Because acts of kindness, and the impact they create, were hard to measure, they were not valued by organisations who valued quantifying worker performance.
- 4. Fear of radical kindness. Organisations can worry that a kind response will have consequences that they are unable to manage such as a higher number of enquiries, a longer time spent with people, or even that kindness was seen as being a 'soft touch' by people.

The Kindness Innovation Network also found other challenges when discussing kindness. The main one was that it could be hard to talk about kindness alongside cuts to the system (this reflects what one Leading The Lives We Want To Live group member observed: "How can we talk about kindness when the system is brutal?"). Another tension was observed in that kindness may be co-opted in order to rely on the voluntary work of individuals or communities, and therefore to withdraw services (Ferguson & Thurman, 2019).

### What you can do

For everyone: Consider your job role against the seven Be Human principles, above. For each of them, ask yourself:

- 1. How do I personally embody this principle in my work?
- 2. How does my organisation embody this principle?
- 3. What do I think needs to be improved?
- 4. What do people with care and support needs say needs to be improved?

This can work well as a team exercise. Once you have your responses, pool them. You can then start to develop a plan based on:

#### **STOP**

What do we need to stop doing?

#### **START**

What do we need to start doing?

#### **STAY**

What do we need to keep doing?

### **Further information**



Watch

North Ayrshire and Carnegie Trust UK have created a short film on The Practice of Kindness (Scottish context).



### Reflect

As part of its learning on Dignity in Care, SCIE has a learning resource on warmth and kindness, with two accompanying practice scenarios.



Read

Research in Practice has a supervisors' briefing on Leading with compassion.

### "Painting the worst picture."

### What this means

While strengths-based working is talked about in social care, the Leading The Lives We Want To Live group reflected on how often, in order to obtain the services they were entitled to, they had to concentrate solely on the negatives.

This deficit-based approach undermines self-esteem and means that the considerable knowledge people have, alongside their carers and families, is not used.

"All we want is an honest conversation. What can we realistically do to improve our situation?"

### The research

The *Care Act 2014 Guidance* explicitly refers to a strength-based approach, as it states local authorities should '…include consideration of a person's strengths and their informal support networks as well as their needs and risks they face' (Department of Health and Social Care, 2023, section 2.22).

The second part of that quote is important, because it highlights that a strengths-based approach does **not** ignore or minimise risk and need. Instead, it takes a holistic approach, where practitioner and person work collaboratively to use that person's strengths as a part of the way to address their needs (Guthrie & Blood, 2019; Sutton, 2020). The deficit (or pathogenic) approach, by contrast, focuses solely on needs and problems and sets out to fix them (Local Government Association, 2020).

Austerity has been identified as the most significant barrier to strengths-based approaches becoming truly embedded (Ford, 2019). Another key reason for the persistence of deficit-based approaches identified by the Local Government Association (2020) can be found in traditional evaluation and reporting. Moving away from counting processes and outputs to something that more meaningfully captures wellbeing outcomes [see Acknowledging and valuing the positives] is a key organisational shift.

Finally, the research that underpins social care can also be guilty of a deficit-based approach. Over a decade ago, McGovern (2011) specifically sought to challenge the deficit model of dementia within her research, which looked at how couples maintained emotional and physical intimacy even with progressive memory loss, difficulties with language and speech, physical frailty and other dementia symptoms. This, she wrote, attempted to challenge the dominant trend in dementia research that '…tends to focus on the losses that result from cognitive and, ultimately, physical decline' (McGovern, 2011, p.679). Since then, other researchers such as Rahmen et al. (2018) have argued for specific recognition of the assets of people with dementia rather than simply measuring and counting their health and wellbeing deficits.

### What you can do

**If you are a senior leader:** Along with the material in Acknowledging and valuing the positives, the Leading The Lives We Want To Live group challenges you to think differently about the communities you serve, and how your organisation measures success.

All organisations will be at different stages in their journey towards strengths-based working. The only way to honestly evaluate how far you have come in this is to consider the experiences of people who draw on social care. The people who made up this group had all had experiences of being treated as their condition, impairment, or caring role rather than as a person, even if an organisation seemed to celebrate strengths-based working. What is the experience of your citizens when it comes to empathy and kindness? How can you translate this into what is measured, how services are developed, and how practice is conducted?

### **Further information**



Read

Research in Practice has published a Strategic Briefing on Developing strengths-based working.

Think Local Act Personal has a report on culture change underpinning strengths-based practice in social care, including numerous examples.

### Co-production in its widest sense

### What this means

There was some frustration in the Leading The Lives We Want To Live group that co-production still had to be a major theme. Why are services not embedding co-production? Group members shared experiences of being excluded from co-production projects for being "too fiery" and/or saying what an organisation didn't want to hear. Projects could get bogged down in detail and the big picture forgotten. One example was shared that an organisation advertised for a 'co-production lead' – but had not co-produced the job description!

Organisations should not be afraid of those they are meant to serve, and we need to make much more progress in mainstreaming co-production in service design and delivery.

"Bloody co-production - I don't want to see it at the top of things we need to do! It was important 15 years ago and nothing has changed"

### The research

Co-production is seen as 'a good thing' for many reasons (efficient use of resources, greater citizen control, sharing power, identifying gaps that are missed by organisations, and so on – all of these themes are explored elsewhere in this evidence review). However, this has been the case for many, many years and still progress on embedding co-production has been slow.

Sutton (2020), in a survey of the research up to that point, identified persistent organisational challenges to effective co-production:

### 1. Ensuring diversity

There is not one 'citizen voice', so ensuring diversity in co-production is essential, in order for the multiplicity of experience to be represented. Research suggests that Black and ethnic minoritised people, younger adults, and people on lower income are under-represented in co-production.

### 2. Availability of sustainable resources

Organisations can under-estimate how resource and time intensive co-production can be, especially at the beginning of a project. If organisations see co-production as creative and unpredictable, they may be more reluctant to invest scarce funding.

#### 3. Achieving true accessibility

Early stages of co-production are vital in terms of building people's confidence and supporting their skills development - so people with lived experience feel able to contribute on an equal basis to people with professional experience. Organisations may also hold meetings in buildings convenient to professionals rather than those with lived experience.

#### 4. Culture and risk aversion

If people feel, even slightly, that their critique of how organisations operate may result in negative consequences, such as having a service or funding withdrawn, they are unlikely to share their opinions. Professionals may also resist giving up their power, which hinders honest opinion sharing.

### 5. The evidence base

Much evidence on co-production comes from evaluations of individual projects, or small-scale studies – so organisations may feel that the evidence base is too weak.

SCIE (2019), in learning from several events from its co-production week with contributions from 120 people with lived experience, also found the following barriers:

- 1. Lack of clear policies and legislation on co-production.
- 2. A lack of knowledge about what co-production means.
- 3. Attitudes, power sharing, and fear of the unknown.
- 4. Organisational culture (which needs to be changed through senior leadership vision).
- 5. Money and resources.
- 6. Accessibility.

The Centre for Ageing Better (2021) looked at how COVID-19 had created new barriers and opportunities for co-production. It found that the following were important:

### 1. Break down barriers to digital engagement.

Don't assume everyone has access to, and is confident in, digital platforms such as Microsoft Teams and Zoom. Be prepared to offer one-to-one training ahead of time, so people can get comfortable. Provide someone as technical support to the project, who people can call directly on the phone.

### 2. Consider alternatives to digital meetings.

People might like to speak on the phone, post thoughts, keep a diary, map out their journey and send photos - or they might very well have their own ideas of how they can contribute!

### 3. Identify and break down barriers in people's lives and living environments.

People may not feel comfortable with their camera on; they may prefer a certain time of day; they may wish to be in smaller digital groups. Ask people and, throughout the project, check that things continue to work for them.

### 4. Adapt your delivery.

People often find shorter sessions online work better than longer ones.

#### 5. Send information in advance.

Providing a short task, or a brief to read, before the session can aid focus.

The report concludes by saying there are now many ways of virtual engagement alongside faceto-face methods of co-production, and this will hopefully be positive in terms of people's choice and control in the future (Centre for Ageing Better, 2021).

You may also find it useful to refer to the sections related to co-production in More Resources, Better Used, Sharing Power As Equals and Communities Where Everyone Belongs - particularly thinking about 'pre-production', where discussions are started earlier with citizens over the parameters of a project, desired outcomes, and agenda setting.

### What you can do

If you are a senior leader: Read the section on 'What this means' again and then reflect on all of the barriers above. Something that comes up again and again is the importance of a clear vision from senior leadership while at the same time working to empower and trust others; and that co-production should not be limited to individual projects, but a mindset running through organisations.

What does this mean to you? How would you respond to the messages from the Leading The Lives We Want To Live group, expressing frustration about the lack of progress on co-production? What pledges could you make to address this?

### **Further information**



SCIE has a webinar on breaking down the barriers to co-production.



### Read

Oxfordshire County Council spent two years embedding co-production (rather than co-producing one-off projects). You can read an evaluation of their experience here (also available in summary and easy read versions), and an accessible handbook so other organisations can learn from their methods.

### What this means

Sometimes, language can betray the low expectations for living fulfilled lives. There can be talk of 'surviving' and 'coping', which immediately sets a low bar. Conversely, when language is strength and rights-based, this creates higher expectations for what can be achieved.

However, we need to be careful how language can be 'hijacked'. An example discussed by the group was the phrase 'personal outcome'. Outcomes can be conflated with need - these are not the same thing, and using them interchangeably undermines the shift towards positive, strength-based language.

### The research

Language isn't an end in itself - it's an expression of thoughts and feelings. The philosopher Ludwig Wittgenstein wrote that 'The limits of my language mean the limits of my world' (quoted in Martland, 1975, p.19) and this very much reflects the experiences of the Leading The Lives We Want To Live group - that only using limited, and negative, words to describe care and support needs diminishes people's experiences. These discussions highlighted once again the core importance of the social model of disability. If professionals started from this perspective, it would help promote more positive language and higher expectations for people with care and support needs.

Yet language can and does change, and it can be manipulated. Giri et al. (2021), in research looking specifically at people with a learning disability, found that the social model of disability had been somewhat co-opted, particularly by the Department for Work and Pensions, who '... seek to use the words once heralded as success for the Disability rights activists and proponents of the social model: such as inclusion, independence and citizenship' (p.98). In other words, simply using the language of the social model of disability without the underlying belief in its principles isn't progress.

Botha et al. (2023), in a study specifically on language and autism, found that language used to describe autism '...has material consequences for autistic people - including stigmatisation, dehumanisation, and violence' (p.870), giving the example of a 2007 American campaign by a charity that aimed to raise awareness of autism in children, but which caused substantial distress and stereotyping. Botha et al. (2023) go on to analyse how autistic people prefer to describe themselves - with 'autistic', 'autistic person', and 'on the autism spectrum' much preferred over 'person with autism'. For autistic people, the 'person with...' formulation seemed to equate autism with medical conditions ('person with cancer', 'person with COVID-19', and so on) (Botha et al., 2023).

People may use numerous, and changing, ways to describe themselves. Being alert to these, always asking the person about their preferred descriptors and understanding things in their own words, is a fundamental part of strengths-based working. As Guthrie and Blood (2019) put it; 'The language which professionals use to describe the individuals they work with has an influence on how those individuals are perceived, and on how they perceive themselves.'

### What you can do

If you are in direct practice: Think about the language you use, or hear, as part of your everyday practice. Do you hear any of the following?

- 'at risk'
- 'did not engage'
- 'isolated'
- 'suffers from'
- > 'coping well'
- > 'struggling'
- > 'demanding'.

(You may also think of other negative words you commonly hear to add to this list.)

How would it feel to hear these words about yourself? Are there other words or phrases you can use without minimising the difficulties people are facing? To help with this reflection, consider again the social model of disability - and think how a perspective that locates society as disabling might use language differently.

For instance, think about the word 'demanding'. Guthrie and Blood (2019) have suggested that this is often used to describe family members or carers. The social model of disability might, instead, consider those family members 'fighting for the rights of their loved ones, and being determined to break down the barriers they face'.

### **Further information**



Use

The Centre for Independent Living shares the language they use to talk about disability and disabled people.

The Alzheimer's Society has a guide, *Positive language*, co-created with people living with dementia, on language to use when talking or writing of dementia.

The British Deaf Association has a factsheet on terminology used to describe or refer to Deaf and hard of hearing people.



Research in Practice has a webinar on Recording strengths-based conversations.

### Human rights - a way to address power imbalances

### What this means

Power was a theme underpinning a lot of the Leading The Lives We Want To Live discussions. This could be overt power that professionals hold - such as financial control, or control over access to a particular service or intervention. But it could also be covert and passive, such as a professional being elusive, or an organisation failing to implement co-production. The asymmetry in the social care relationship needs to be acknowledged, as a first step.

Greater knowledge of, and use of, human rights is a way to address some of this power imbalance. The group believed that the articles of the Human Rights Act (1998) '... should be learned like a nursery rhyme' and, along with the UN Convention on the Rights of Persons with Disabilities, human rights should be linked with every plan and every action.

> "We know what good practice looks like. The imbalance of power means that we are not heard."

### The research

Much of the research on power is covered in the Sharing Power As Equals key change (it may be particularly relevant to read the sections Power has many faces and Power is subtle and unspoken).

Human rights legislation is unique because it focuses on humanity - the basic freedoms and protections we should all have because we are human (Elliott, 2017) rather than being contingent on our identity, behaviour, or eligible needs. It is potentially, therefore, a potent way to equalise power relationships when thinking about adult social care. The British Institute of Human Rights (2013) found that increasing a focus on human rights in health and social care would support:

- > More person-centred practice.
- Reduced risk of complaints and litigation in the longer-term.
- > Improved decision-making.
- > More meaningful engagement.
- Broader range of minoritised groups having their voices heard.

The report also said that a human rights approach promoted 'power not pity', arguing that accessing public services often inherently involved an imbalance of power but 'human rights can provide a powerful language for the conversations that need to take place, moving away from needs or charity to fulfilling rights and duties. This can be empowering for all involved' (p.8).

However, in practice, there can be a gap between rhetoric and reality. Kinderman et al. (2018) found that staff training in human rights, in itself, did not improve the wellbeing of the people staff worked to support (in this case, people living with dementia). The study suggested that more staff ownership of a human rights approach was needed, rather than a solely top-down approach. In a study concentrating on social workers in an integrated mental health service, Meadows and Moran (2022) found that, while all participants recognised human rights as central to the work they did, there was limited knowledge of human rights legislation, little explicit training, and a lack of human rights discussion in supervision.

The *United Nations Convention on the Rights of Persons with Disabilities* (UN CRPD) was adopted by the UN General Assembly in December 2006. The UK ratified the Convention in 2009. By following UN CRPD, the UK agreed to protect and promote the human rights of disabled people, including:

- > Eliminating disability discrimination.
- > Enabling disabled people to live independently in the community.
- > Ensuring an inclusive education system.
- > Ensuring disabled people are protected from all forms of exploitation, violence and abuse. (Abreu, 2022)

Kim (2010) argued that the UNCRPD could be a significant lever to strengthen human rights-based practice and move conversations towards disability rights and inclusion. However, UK-wide progress on UN CRPD has been slow, with Inclusion London finding that the situation for disabled people has worsened since 2017 (which was when the UN last looked at the UK's progress), including the impact of COVID-19 measures (which discriminated against disabled people). Overall, the report found that there was insufficient monitoring of the UN CRPD, which was also inhibiting progress (Inclusion London, 2022).

### What you can do

If you are in direct practice: Research in Practice has a Frontline Briefing that can support you in taking a rights-based approach to your assessment work (this briefing is also helpful for people working in social care who don't assess people). Questions that support a human rights approach in your direct work include:

### Broad questions on dignity and equality

- What matters most to you?
- What does a good life look like to you?

### Questions related to Article 2 (freedom from inhuman and degrading treatment)

- > What is stopping you from living your life the way you want to?
- > What has happened to you? (This is a trauma-informed question that allows exploration and growth, and does not undermine someone's dignity.)

## Questions related to Article 5 (Liberty and security) and Article 8 (Respect for private and family life, home and correspondence)

- What makes home for you?
- > Who is important to you?

### Questions related to Article 14 (Prohibition of discrimination)

- > Can you tell me a bit about your history?
- > What's meaningful to you in your life?

Consider these questions, and think of others that could relate to the *Human Rights Act* (1998) and the *United Nations Convention on the Rights of Persons with Disabilities*. How can you include more of these in your practice? Whose support do you need to get in order to do this?

If you are a supervisor: The research has clearly identified that having a supervisor support learning and development around human rights, and keeping it on the agenda in supervision sessions, is key to getting this approach in practice. You might consider the following:

- > Speaking to those you supervise about how they currently view and use human rights in their practice.
- > Team awareness-raising, including posters, shared links, and discussions.
- > Scheduling agenda items on human rights in team meetings and individual supervision discussions.

If you are a senior leader: Research in Practice has published a Leaders' Briefing, on *Embedding* human rights in adult social care. It contains many reflections and ideas for taking this work forward. The five key steps to take are adapted below:

#### 1. Consultation

Find out what is important to citizens and staff. What do they say are the fundamental things your organisation needs to be doing in order to treat people with dignity and respect?

### 2. Identify the rights you should be protecting

Translate these views into a list of specific rights that are important to people, and compare this with your legal duties under the Human Rights Act 1998, and with the principles of the UN CRPD.

### 3. Create a quality standard

Agree a set of staff behaviours that protect and promote human rights, and which can be used to judge the effectiveness of your organisation.

### 4. Support your staff

They will need to feel supported in adopting this approach (consider the research above that suggests a human rights approach can be impeded by a lack of confidence and little line management support).

### 5. Monitor your success

And then build on what is working well!

Linking Human Rights with assessments and plans, and adapting the forms so they explicitly prompt practitioners to consider this, is another positive step (for an example of this, see the Mersey Care Keeping Me Safe And Well manual, co-produced with people with learning disabilities).

### **Further information**



Watch

The Equality and Human Rights Commission has clear information and bitesize videos on human rights and the Human Rights Act 1998.

There are several webinars and films from Research in Practice on human rights and adult social care. This webinar looks generally at embedding human rights across social care; this short film considers human rights and dementia; and, in two filmed presentations, Professor Chris Hatton looks at health inequalities and human rights.



Read

The British Institute of Human Rights has a Practitioners' Guide to dementia and human rights.

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