

Whose life is it anyway? Countering epistemic injustice in social service scrutiny and improvement by involving people with personal experience

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The importance of involving people in the design and delivery of their own care and support is a well-established principle of social work and social care. It is closely associated with issues of autonomy, self-direction, and the powerful idea that people possess a human agency which allows them to shape and determine their own lives. This underpins Scotland's new health and social care standards which, written from the perspective of a person experiencing care, establish the clear expectation that people should be “fully involved in all decisions about my care and support”ⁱⁱ.

Because modern regulation of social services is concerned with understanding and assessing the impact these services have on people's wellbeing and supporting improvement, specific issues arise about how and why people should be involved. As well as legal and professional imperatives, the importance of involving people who experience care and support can be located within recent thinking about social justice and its absence, social injustice.

Regulation and power dynamics

Regulation of any public service presents a three-way power dynamic between the regulator, the regulated, and people using the regulated service: in different interactions, each party may exercise or cede power in relation to another. Understanding these potentially complex power imbalances, and responding appropriately, is an important part of any regulator's roleⁱⁱⁱ. Modern approaches in social care and social work, both at a service and professional level, seek to shift regulation from a compliance-based activity to one which is more inquisitive of performance, impact and outcomes for people experiencing care. By making people experiencing care and support the focal point of scrutiny and improvement, regulators seek to understand what life is really like for them. It is insufficient for a scrutiny and improvement body to act on behalf of people experiencing care, without involving those people in its work. Regulators must therefore reflect carefully on potential power imbalances, and seek to ameliorate them: to effectively assess impact and outcomes for people, it is necessary to empower people to freely share their perspectives on the quality they themselves experience.

The practice of scrutiny

This gives rise to important questions about the practice of scrutiny and improvement itself: how does a inspector actively avoid supplanting their own views in place of the views of people in whose name they act, whilst at the same time bringing a professional judgement to the circumstances they are inspecting? Resolving this complex

tension is an art, not a science, and can be aided by significant understanding of the professional practice they are regulating. It can also be helped by actively involving people who experience care in the scrutiny process itself, so that the regulatory lens is firmly focused on those people's experiences and interests.

The importance of adopting such a lens is reflected in the statutory duty of user focus which applies to specified scrutiny bodies in Scotland^{iv}. Recalling the co-design movement, legislation requires “the involvement of users of scrutinised services in the design and delivery of scrutiny functions in relation to those services and the governance of the listed scrutiny authorities”. This represents a powerful and broad driver for involving people who experience care and support in the assessment of quality about such services, in numerous ways. Even if were not a legal requirement, however, this is surely something that a social work and social care regulator would wish to do: it reflects the core practice of those professions.

Epistemic injustice

Recent philosophical thinking about justice and injustice provides an arresting perspective on why involving people in scrutiny and improvement is important. Fricker (2007) has proposed the concept of epistemic injustice: the idea that someone may be wronged specifically in their capacity as a knower. People may experience injustice not just because of their personal circumstances, but in their capacity as someone with specific first-hand knowledge about their own experiences. Fricker suggests there are two distinct types of epistemic injustice. Testimonial injustice occurs when a speaker's account is dismissed or disbelieved because the speaker is viewed as having less credibility than they actually ought to be accorded. This may happen because of negative stereotypes attaching to the speaker. Hermeneutical injustice is of a different kind, arising from the lack of interpretative resources through which particular experiences can be understood. This happens because the speaker belongs to a hermeneutically marginalised group, so their social experiences are exclusively understood via some other, usually dominant, interpretative framework.

Fricker explains that the:

basic idea is that a speaker suffers a testimonial injustice if prejudice on the hearer's part causes him to give the speaker less credibility than he would otherwise... [there is also] injustice as stemming from... a gap... in our shared tools of social interpretation where... the unequal disadvantage derives from the fact that members of the group that is most disadvantaged by the gap are, in

some degree, hermeneutically marginalized—that is, they participate unequally in the practices through which social meanings are generated.

That injustice may be perpetuated because people's description of their own experience may not be believed, or because others lack the interpretive framework to understand it, is potentially disturbing for any social work or social care professional, and for a regulator charged with furthering improvement in these sectors. The thought that previously unarticulated forms of injustice exist which may result in the marginalisation of the very people the regulator is working on behalf of requires a re-examination of how the scrutiny and improvement process involves people and amplifies their voice.

The relevance of epistemic injustice to the caring professions has not been lost. Carel and Györfy (2014) describe the tragic consequence of epistemic injustice in the context of child protection. In respect of healthcare, Carel and Kidd (2013) argue that:

Ill persons can suffer testimonial injustice through the presumptive attribution of characteristics like cognitive unreliability and emotional instability that downgrade the credibility of their testimonies. Ill persons can also suffer hermeneutical injustice because many aspects of the experience of illness are difficult to understand and communicate and this often owes to gaps in collective hermeneutical resources.

These risks can also present in social care or social work where no specific medical illness is at play. Effective multi-disciplinary practice guidance can be interpreted as trying to counter epistemic injustice: across all social services, including early learning and childcare, national standards direct professionals to practice in a way which gives effect to the statement “I am recognised as an expert in my own experiences, needs and wishes”^v. In adult social care, injustice may be reduced by recognising that what has previously been considered “challenging behaviour” in people living with dementia is more accurately understood as their stress and distress^w. The risk of epistemic injustice also presents in the design of services, where those making strategic decisions may be a step removed from the delivery of care and support and, therefore, the people it affects most.

Awareness of epistemic injustice raises important questions for scrutiny and improvement of social services, as well as delivery. Inspectors and improvement advisors must practice their work in a way which seeks to understand the views and perspectives of people who are themselves experiencing care and support, at a deep level. This is particularly important when taking a person-led, rather than service-led, approach to inspection. Where a person uses many care services, or moves between settings (for example, in integrated health and social care, or early learning and childcare), it may be that a service on its own is satisfactory, but collaboration and communication between them is ineffective. This is something that a person experiencing care would experience acutely, but others would not necessarily see without understanding their experiences.

This does not require a change to current scrutiny practice, but a continued strengthening of it. Scrutiny and improvement bodies are experienced at using tools and approaches to understand the personal experience of people, and involve them in scrutiny and improvement activities. Many predate the literature's accounts of epistemic injustice, but understanding how involvement and user focus can reduce the risk of epistemic injustice provides a helpful theoretical framework to underline its importance and may accelerate the development of new interpretive frameworks to understand the experiences of seldom heard or marginalised groups.

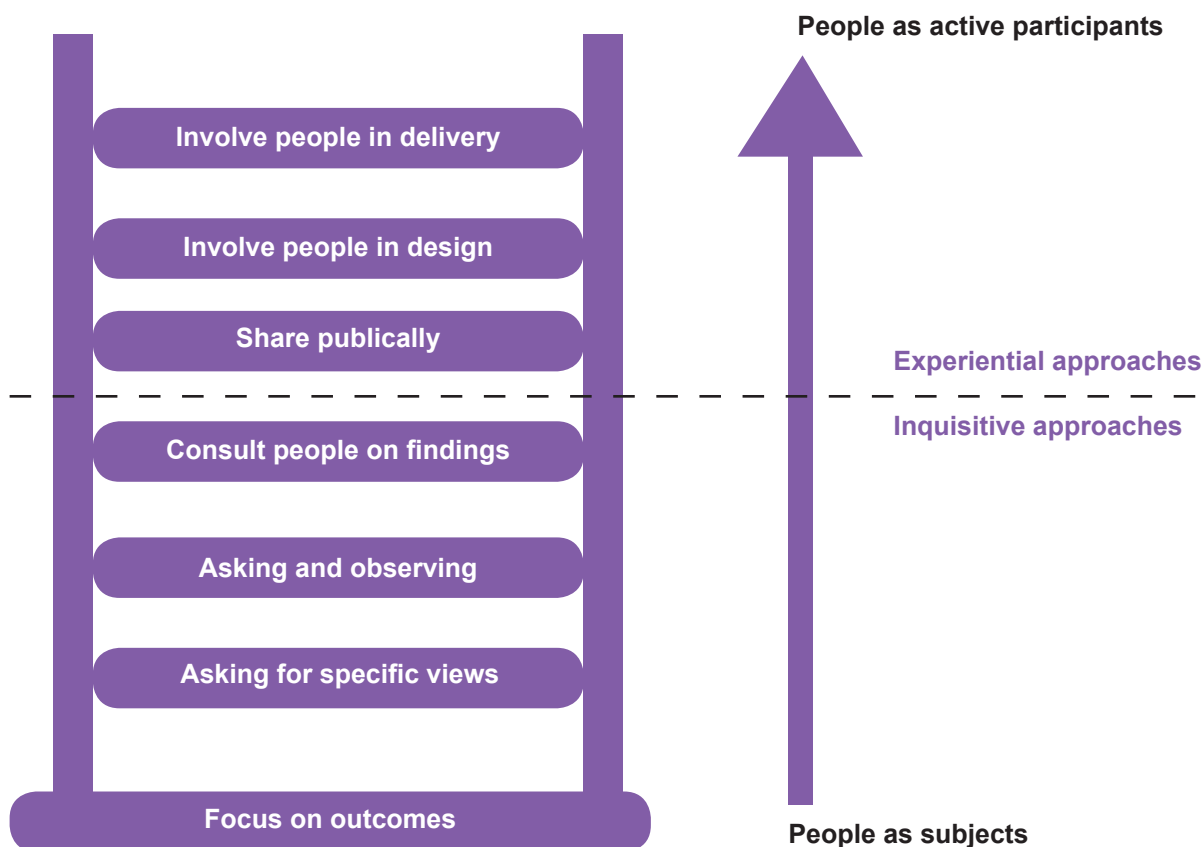
Tools to support the duty of user focus in scrutiny

Because it is both necessary and desirable to involve people who use services in the scrutiny and improvement of those services, inspectors must be able to reach for a range of tools suitable to the setting. The purpose is to help the inspector understand the lived experience of a person by involving them in the scrutiny process, but should also be seen as an extension of a long tradition of citizen empowerment, particularly evident in the memorable disability rights slogan “nothing about me without me”. These tools may be inquisitive or experiential. Inquisitive tools are those which an inspector can use themselves to understand people's experience. Experiential tools are those which involve people with lived experience to directly take part in scrutiny and improvement activities.

The Care Inspectorate's approaches to the duty of user focus can be presented as a conceptual ladder of involvement, consciously recalling the ladder of citizen participation proposed by Arnstein (1969). This ladder illustrates a progression of approaches, moving from regarding people as the subjects of scrutiny to enabling them to be active participants in it.

The general shift in scrutiny and improvement approaches towards a **focus on outcomes** for people, and the difference care provision is making to these, is the foundation stone for the duty of user focus. It provides a grounding to ensure that, whilst maintaining appropriate scrutiny interest in effective processes and the use of evidence-based guidance, quality is primarily assessed through the lens of people's personal experiences, rather than compliance with a set of orthodox principles. It is insufficient to simply check inputs such as policies and procedures, or activities such as care and clinical delivery, without assessing the impact these are having on people's experience and outcomes. If an inspector wishes to provide public assurance about the quality of care, and support improvement where necessary, they need to understand the impact of care on people. Understanding these experiences is the foundation of supporting learning and improvement. While this paper primarily addresses justifications for, and approaches to, hearing user voice, responding to it in order to plan improvements is equally necessary.

Fig 1. A ladder of involvement in scrutiny and improvement to counter epistemic injustice



Inquisitive approaches

Asking for specific views helps identify what people report as being high or poor quality, and allows inspectors to follow the evidence to arrive at professional judgements. In any year, the Care Inspectorate receives responses to written surveys from over 60,000 people who experience care and their carers. This information helps to plan scrutiny and improvement interventions, largely identifying areas which may require further review. While there are undoubted benefits to this approach, there are some limitations too. Some people may lack capacity to recall or share their experiences. People may fear negative repercussions from speaking up, or may lack of understanding or faith in the process. There may be bias in who can participate; they may not be reached or they may speak or use a different language to the one in which the questions are asked. These limitations are particularly relevant when considered in the context of potential epistemic injustice.

This is why a less pre-defined approach of **asking and observing** is important. Scrutiny which provides only professional-to-professional dialogue risks perpetuating, not addressing, epistemic injustice. Modern inspection practice seeks to understand the views and experiences of people, in free-flowing conversations which allow them to direct and control the agenda; this is materially different to answering questions which have been selected before the inspection commences. The role of the inspector is not simply to report back what people say, important though that is, but to synthesise and use this information in making independent evaluations of the quality. To this

end, triangulation of personal testimony from people experiencing care with other evidence is important. Tension may arise where the views of people experiencing care do not concur with the synthesised professional judgement of the inspector: the inspector may evaluate care as not making the impact it should, or assess that outcomes for people could be better, even where the person experiencing care is content. While such situations may be complex, that is no reason to eschew them: not seeking the views of people would exacerbate complexity, not avoid it.

Some people experiencing care may not be able to verbalise their feelings. In 2014, the Care Inspectorate deployed the Short Observational Framework for Inspectors (SOFI2), an observation tool which inspectors use over a defined period of time to record the quality and nature of interactions between people experiencing care and care staff. Developed by the University of Bradford and the Care Quality Commission in England, this supports structured observation of the quality of interactions. It has particular application where people are not able to verbalise or otherwise communicate with the inspector. Whilst designed for use in care homes for older people, the Care Inspectorate is, at the time of writing, testing the approach in early learning and childcare settings; initial results are favourable.

The model here presents a step whereby inspectors **consult on findings**; this can be undertaken iteratively as part of the inspection, or prior to finalising the scrutiny process. All these approaches above are important, but locate people experiencing care as the subject of scrutiny.

Experiential approaches

This paper argues that a more powerful expression of the duty of user focus, and potentially a more robust way to address epistemic injustice, can be achieved by seeking to empower people who experience care as active participants in the scrutiny and improvement process.

There is emerging interest in approaches which encourage people to **share publically** their experiences, positive and negative, about care. The Scottish Government has supported Care Opinion to facilitate people to tell their personal stories about care^{vii}. These are published online. The organisation works with providers of care to ensure that the shared stories are also passed directly to people responsible for assuring the quality of provision. The approach extends, currently, across all adult social care and health provision and is publically funded for use within the NHS in Scotland.

The Care Inspectorate, like other organisations, has committed to **involve people in design** of scrutiny and improvement. An Involving People Group, comprising people who experience care and carers, advises the organisation on its approach across a range of strategic and policy issues. These include what the national standards for care should be, how inspections should be conducted, and the kind of things that are important for people to know from an inspection report. The purpose of this group is to 'envoice' people who experience care, and carers, in the scrutiny and improvement processes which affect them and other people, and to correct power imbalances which can exist in the delivery of public services. These arrangements are augmented by an involvement strategy and co-produced involvement charter. At a governance level, the Care Inspectorate's board includes members with personal experience of care and support, and carers.

Perhaps the most important way a scrutiny body can give effect to the duty of user focus is to **involve people in the delivery** of scrutiny and improvement activity. The Care Inspectorate has, at any one time, some seventy inspection volunteers. These are people who experience care and support, and carers. They accompany the inspector on an inspection and take part in the inspection itself. They observe, speak with people, and may interview staff and managers. A training programme and small team of support co-ordinators facilitate and enable them to participate in inspections. These volunteers may have past experience of care and support, may have familial experience, or may currently experience care and support themselves.

Case study

In 2017, the Care Inspectorate involved four people with a personal diagnosis of dementia to join dementia-focused inspections in residential care settings. This involvement provided many insights and motivators for small but powerful changes within care homes. For example, as a result of the observations and perspectives of these inspection volunteers, one care home made changes to the lighting in corridors, another manager bought new soft furnishings to create a more homely environment and another care home made changes to the mealtime experience to make this more dementia-friendly.

In addition, a team of about twelve young inspection volunteers support inspections of services for children and young people. They are specially trained people aged 18–26, who themselves have personal experience of care. Most have lived in foster care, residential homes or with extended family in a formal kinship care arrangement. Some have used aftercare support, disability services or experienced homelessness. These volunteers go along on inspections and talk to young people about their experiences. They offer valuable insights as they can look at services through the lens of a young person and not a professional, and they often ask practical and challenging questions during inspections based on their own experience of care. Some inspectors report that children and young people feel they can talk more freely to another young person than they can to an adult. If so, this helps hear and amplify the voice of people experiencing care and support. As well as interviewing children and young people, the volunteers undertake a wide range of activities as part of these inspections such as assessing integrated children's services plans, which set out how local partnerships are working together to improve children's lives. They may also look at websites and leaflets providing advice and guidance for young people to check whether they are accessible, accurate and easy to understand. They interview local politicians and senior managers to find out about the services provided and how they demonstrate the difference they are making, helping to identify good practice that other services and partnerships can learn from.

Conclusions

There are many reasons why regulators should involve people who experience care in scrutiny and improvement. It is a legal requirement, it enhances the work of inspectors, and people experiencing care have the right to be involved in every aspect of their own lives. However the ambition of tackling epistemic injustice provides a fresh justification for actively involving people in regulatory activity. Regulators' social obligations cannot be fully realised without continually reflecting on regulatory practice and the extent to which it reduces epistemic injustice.

This paper presents practice and evaluative comments based on the experience of one scrutiny and improvement body. This is important, but the duty of user focus would benefit from broader evaluation and research into impact, particularly if it were undertaken across different organisations, and focused on providing evidence about

how the duty can best support scrutiny and improvement to be practised in an epistemically just way.

With increasing community empowerment, and the importance of place-based leadership in local neighbourhoods, it is likely that the involvement of people with an interest in public services in local communities will grow. This is a challenge for sectorally-drawn scrutiny and improvement bodies, but certainly not an insurmountable one. Involvement and hearing user voice has potential to mitigate epistemic injustice and, in so doing, contribute positively to experiences and outcomes for people in local communities.

References

Arnstein, S.R. 1969. 'A Ladder Of Citizen Participation'. Journal of the American Planning Association. Vol. 35, no. 4, pp. 216-224.

Fricker, M. 2007. Epistemic Injustice: Power and the Ethics of Knowing. Oxford University Press.

Carel, H., and Györfy, G. 2014. 'Seen but not heard: children and epistemic injustice'. The Lancet. Vol. 384, no. 9950, pp. 1256–1257.

Carel, H., and Kidd, I.J., 2013. Do Ill People Suffer Epistemic Injustice? Bristol University. Obtained from:

https://research-information.bristol.ac.uk/files/53583496/Do_ill_people_suffer_epistemic_injustice_FINAL.pdf.

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Declaration of interest

The author is related to the author of Carel (2013 and 2014).

ⁱThe Care Inspectorate, formally Social Care and Social Work Improvement Scotland, is a non-departmental public body charged with scrutiny and improvement support in respect of social work, social care, early learning and childcare, children's services, and community justice.

ⁱⁱSee www.newcarestandards.scot

ⁱⁱⁱThe Care Inspectorate, for example, positions one of its four strategic objectives as being about empowering people to understand the standards they should experience and helping to make sure their voices are heard.

^{iv}Sections 112 and 113, Public Services Reform (Scotland) Act 2010.

^vHealth and Social Care Standards 1.31. See www.newcarestandards.scot

^{vi}See, for example, <http://dementia.stir.ac.uk/blogs/dementia-centred/2018-02-20/challenging-behaviour-bpsd-and-stress-and-distress-potato-po-ta>

^{vii}See www.careopinion.org.uk

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