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Canolfan Polisi Cyhoeddus Cymru

Lived experience evidence in disability policy making

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Summary

- This report investigates the role of lived experience evidence and co-production in disability policy making in Wales.
- Welsh Government has specifically committed to including lived experience evidence in policy making. This commitment was reinforced in disability policy making following the publication of the Locked Out Report in 2021.
- Terminology surrounding the topic often lacks clear definitions, with co-production and lived experience frequently conflated or used interchangeably.
- Defining key terms at the start of projects and ensuring roles and responsibilities are transparent are key.
- The report identifies a consensus that lived experience should inform policy. However, there is debate over whether lived experience constitutes evidence and if it should be valued as highly as more traditional evidence forms.
- It recommends that lived experience evidence should be considered as 'one tool in the evidence toolbox' and given equal validity as traditional evidence.
- Despite commitments to co-production and including lived experience evidence, the report identifies persistent barriers to participation. These include the conflation of professional expertise with lived experience, power imbalances, and a lack of trust in policy makers and public institutions among citizens.
- It recommends that knowledge brokers and Welsh Government work to build trust with more marginalised communities to facilitate their inclusion.
- The report observes a lack of consensus on integrating different evidence forms. Some participants use triangulation as a method of validation
- Co-productive approaches to evidence integration and synthesis, involving people with lived experience, are advocated. This may require additional time and resources from the start of projects.

Introduction

It is a stated aim of policy makers in both Wales and the wider UK to incorporate citizen voices in their evidence-gathering activities. The Five Year Forward View by NHS England states that it is important to engage with “communities and citizens” in the formulation of health policy (NHS 2014, as cited in Crane 2018, p.9). Welsh Government, in a similar vein, has committed to including lived experience voices in policy making. This approach ensures that those most impacted by policies are heard (e.g., Welsh Government 2021a; Welsh Government 2021b). In the realm of disability policy making, the commitment to this inclusive approach was reinforced following the Locked Out Report (Foster 2021). The report, a result of an enquiry commissioned by Welsh Government, delves into the experiences of disabled individuals during the Covid-19 pandemic.

This report addresses several key questions:

- What role does evidence based on lived experience play in disability-related policy making, as viewed by policy makers, knowledge-brokering organisations, and grassroots groups?
- In what manner is evidence from lived experiences conceptualised and utilised?
- How effectively are different types of evidence (research, professional, tacit, and lived experience) integrated in a collaborative and co-productive manner?

The report commences with definitions of key terms. Subsequently, it explores existing literature on citizen and lived experience knowledge, the role of knowledge brokers, evidence hierarchies, and the concept of co-production. The methods employed in this study are then outlined, followed by an analysis of the findings in the context of the reviewed literature. The report concludes with a summary and offers recommendations for disability policy making and knowledge brokering.

Defining terms

Rather than adhering to the legal definition of a citizen, which in Britain is someone with the right to reside in the UK, work in the UK, and apply for a British passport without restrictions (see GOV.UK 2023), we adopt a broader approach, encompassing all members of the public who might be involved in the policy making process. Consequently, all people with lived experience will also be considered citizens. However, not all citizens are individuals with lived experience. In this context, we align with the approach common in healthcare research

and practice (e.g., Vázquez et al. 2023), including only those who truly have lived experience of a specific policy area. For instance, in disability policy, this would encompass disabled individuals and their families or carers, but not practitioners with professional experience in disability. These distinctions, based on literature and the author's own lived and professional experience of being included in the policy making process as a non-executive director of a disabled people's organisation and an individual who is openly neurodivergent, are critical to ensure that differences in experience are clearly distinguished.

It is frequently claimed that policy makers have consulted with individuals who have lived experience when, in reality, their experience is based on professional knowledge. While valuable, it is essential to distinguish between these types of expertise, especially when considering who is given a seat at the decision-making table. People with lived experience provide local, tacit knowledge (Goulart and Falanga 2022). Knowledge brokers recognise that this practice-based, tacit knowledge is valuable, especially in understanding how policy and public service provision can be implemented (Ward et al. 2009; Best and Holmes 2010). However, this form of knowledge is often deemed less valid than other types, such as technical knowledge (Heath and Mormina 2022).

Citizen knowledge and involvement

The ways in which citizens are engaged in policy making and its implementation are multifaceted. This includes being heavily involved in agenda-setting and co-governance (Goulart and Falanga 2022), serving as lay members on committees or boards (Edwards 2014), participating in collaborative research such as participatory action research (PAR) (Greenhalgh and Wieringa 2011; Heiskanen et al. 2014), proofreading research questionnaires (O'Shea et al. 2019), and as participants in qualitative research (Exley 2021; Sesan and Siyanbola 2021).

The value of citizen engagement is viewed inconsistently. It can have a positive effect, as sharing knowledge contributes to active citizenship (Entradas 2016), and can make policy making inclusive and empowering (Alnabilsy and Levin 2023). However, not all discourse around citizen engagement is positive. Some authors are openly critical of the process, describing it as "antagonistic" (Beresford 2019, p.8). Predominantly, it is seen or described as "tokenistic" (Crane 2018, p. 10), a "marginal role" (O'Shea et al. 2019, p.10), something that "can change little" (Rose and Kalathil 2019, p.5), and could be considered "lip service" (Boivin et al. 2014, p.321), with limited impact on the policy making process and its practical implementation (Conklin et al. 2015; Crane 2018; O'Shea et al. 2019; Richards and Scowcroft 2020).

Additionally, some perceive the public as incapable of being valid knowledge producers, an instance of epistemic injustice (Fricker 2007). For example, in space policy making, some

scientists argue that citizens could be “manipulated by ... the general media” (Entradas 2016, p.607), implying “that the public can be misled but not scientists or the government” (ibid, p.608). This view is partly due to the construction of ‘experts’ as more trustworthy than the ‘public’, a stance evident in healthcare where the legitimacy of people labelled ‘service users’ is diminished compared to those called ‘experts by experience’ (Rose and Kalathil 2019).

However, there is recognition that the legitimacy of knowledge is not static but context-dependent, including on whom the knowledge is brokered for (Gough 2020; MacKillop et al. 2023; MacKillop and Downe 2023). Local knowledge is sometimes considered more legitimate (Boivin et al. 2014) as the needs that policy makers must understand vary by location and “require understanding the local needs and perspectives” (Juri et al. 2022, p.3). This indicates that localised citizen knowledge could be an asset to knowledge-as-evidence for policy making (Metz et al. 2019).

Citizen knowledge can originate from multiple sources, including individual stories and information gathered from their communities (Boivin et al. 2014). It is argued that this knowledge should be considered “valuable expertise” (Crane 2018, p.14) by policy makers. By supporting citizens to provide knowledge-as-evidence, and if this includes information from the wider community, it can be afforded greater credibility (Boivin et al. 2014). This support could be facilitated by knowledge brokers (Juri et al. 2022), or through co-production.

Lived experience knowledge and involvement

Research indicates that many policy makers understand the value of knowledge derived from lived experience, both for policy making and for practical policy implementation (Greenhalgh and Wieringa 2011; Henderson and Kendall 2011; Boivin et al. 2014; Beckett et al. 2018; Beresford 2019; Culwick et al. 2019; Cooke et al. 2021; Juri et al. 2022). Additionally, some practitioners prefer lived experience as their primary source of knowledge (Steel et al. 2023). Incorporating lived experience knowledge as evidence acknowledges the complexity of multiple realities, exposing policy makers and practitioners to diverse perspectives (Beckett et al. 2018). It helps prevent the “narrowed and constrained” policy and practice outcomes that can arise from traditional, reductionist science (SurrIDGE and Harris 2007, p.310).

However, others point out obstacles to incorporating lived experience evidence in both policy making and practice literature. The barriers mentioned are diverse. Some argue that “language and culture” barriers inhibit participation (Alnabilsy and Levin 2023, p.2), while others cite financial constraints in reaching the necessary audiences (Beresford 2019; Rose and Kalathil 2019), lack of resources to support participants with lived experience (Beresford 2019), exclusions due to equality issues including disability (Beresford 2019), time

constraints (Duncan 2017; Richards and Scowcroft 2020), and concerns about increased “risk” without further explanation of what this entails (Exley 2021, p.13).

Knowledge brokers

While we have discussed the various ways citizens are involved in policy making, these activities are often perceived as distinct and separate from the work of knowledge broker organisations (KBOs). KBOs facilitate policy making by making evidence accessible and understandable to policy makers. Often characterised as ‘boundary spanning’ (MacKillop et al. 2023; Neal et al. 2023), KBOs engage in evidence syntheses and mobilisation to bridge the research-policy gap. However, despite their role in informing policy in contexts where including lived experience knowledge and citizen involvement is mandatory, there is scant reference to these elements in KBO literature. This oversight might stem from “the continued belief that policy options must be framed in terms of evidence to be acceptable” (MacKillop et al. 2023, p.2).

The distinction between ‘evidence’ and ‘knowledge’ is not always clear. Knowledge brokers and other boundary-spanning entities often refer to each concept separately, with ambiguous mentions of “right kinds of evidence” (Best and Holmes 2010, p.151) and “good evidence” (MacKillop et al. 2023, p.5). This suggests a contrast with other forms of knowledge or evidence that, in the view of knowledge brokering organisations, do not meet these criteria.

Evidence hierarchy

It is common for there to be some construction of a status hierarchy of different evidence types (see figure 1 in Smith-Merry 2020, p.307), including the trope that ‘objective’ quantitative academic research is often privileged over qualitative studies (Rose and Kalathil 2019; Isett and Hicks 2020). However, the notion that research knowledge is objective is contested (Greenhalgh and Wieringa 2011; Rose and Kalathil 2019; MacKillop et al. 2020; MacKillop et al. 2023), as is the idea that ‘objective’ knowledge is inherently more valuable (Beresford 2019). Stemming from evidence-based medicine, the evidence hierarchy is used as a template for evidence-based policy. Nevertheless, there is recognition that lived experience should also be considered alongside a range of other evidence forms (see Oliver and Pearce 2017 for more information). Despite this recognition, research knowledge still tends to be placed above citizen knowledge in the evidence hierarchy (Greenhalgh and Wieringa 2011; Juri et al. 2022).

Amidst often vague conceptualisations, there is some acknowledgement that “powerful network insiders” shape the meaning of evidence, particularly what is considered “legitimate” (Exley 2021, p.3). KBOs offer some definitions of evidence, with some claiming they do not

adhere to “hierarchies of evidence” and include both qualitative and quantitative syntheses (MacKillop et al. 2023, p.6), alongside “gray literature” and peer-reviewed academic journal articles (Neal et al. 2023, p.15). This suggests that knowledge – and subsequently evidence – encompasses more than just academic research (Ward et al. 2009; Best and Holmes 2010; Kislov et al. 2017).

While not all KBOs and knowledge producers subscribe to a knowledge hierarchy, some still claim that including citizen knowledge as evidence reduces credibility (Entradas 2016; Cooke et al. 2021), and others do not consider citizen knowledge legitimate (Beresford 2019). Additionally, there is an apparent hierarchy between “actual empirical evidence” and the lived experience voice, which is often seen as “some stories that bring it to life” (Sanders 2023, p.181).

There is a recognition that those with more power have a greater influence in deciding what knowledge counts as evidence and whose knowledge is excluded (O’Shea et al. 2019). For example, individuals such as those with dementia and neurodivergent people are often seen as “unwanted voices” (Beresford 2019, p.9) and are typically disempowered in knowledge-gathering activities, including consultation and participation in research (den Houting et al. 2021). Moreover, people in positions of relative power may ‘support or challenge’ public participation in policy making and its practical implementation (Greenhalgh and Wieringa 2011; Boivin et al. 2014; Edwards 2014; Rose and Kalathil 2019; Alnabilsy and Levin 2023). KBOs must be aware of their influence when conducting evidence-gathering and synthesis, as they determine what is credible, useful, and legitimate (Best and Holmes 2010; Bornbaum et al. 2015; Gough 2020; MacKillop et al. 2023; MacKillop and Downe 2023; Neal et al. 2023). Thus, they might contribute to upholding knowledge hierarchies if they exclude lived experience evidence.

Co-production

Co-production is particularly relevant to disability policy making, underscored by the disability activism slogan ‘Nothing about us without us’ (Bertilsson Rosqvist 2019). Furthermore, disability activists have been crucial in creating space for the lived experience voice, as evidenced by seminal works such as the edited collection *Stigma: The Experience of Disability* (Hunt 1966). This collection of essays was one of the first written by disabled people to not solely describe their conditions, but to discuss the *meaning* of being disabled in and by society.

There is no single definition of co-production. In this report, we focus on co-production that includes people with lived experience (Duncan 2017; Kislov et al. 2017; Beckett et al. 2018; Metz et al. 2019; Laird et al. 2020; Lamont and Maxwell 2023). Despite extensive literature

on co-production with people who have lived experience in health policy and practice, no examples were found in disability policy making.

Co-production with citizens is viewed as a means of democratising knowledge (Juri et al. 2022), leading to a “plurality of knowledge” influencing policy, which is believed to yield beneficial outcomes (Duncan 2017; Beckett et al. 2018, p.3), including greater policy success (Exley 2021). Moreover, co-production is seen as enhancing the legitimacy of research and policy making (Reyers et al. 2015; Duncan 2017) and as shifting perspectives on what constitutes ‘legitimate knowledge’ (Beckett et al. 2018). This shift potentially creates room for the inclusion of lived experience knowledge as evidence, rather than merely as illustrative stories accompanying research evidence.

However, realising the intended outcomes of co-production can be challenging for all involved, especially when different workplaces and cultures use ‘different languages’, for example, having varying definitions of concepts such as chronic illness (Culwick et al. 2019). A related issue is the diverse epistemologies – understandings of how we know what we know – among co-production groups (Lamont and Maxwell 2023), with some authors noting that “what counts as knowledge is policed” (Rose and Kalathil 2019, p.5). This suggests that current co-production approaches within these contexts may not effectively include lived experience knowledge as evidence, and that power dynamics persist despite co-production’s aim to democratise knowledge. “[T]ensions” resulting from unequal power dynamics often relegate those with lived experience to primarily “driving the outputs”, suggesting their role is more dissemination than knowledge production (Lamont and Maxwell 2023, p.140).

More concerning are reports that co-production can negatively impact the inclusion of lived experience knowledge as evidence. For example, co-production with citizens can divide communities if citizen participants’ contributions are shaped more by the “rules and regulations” of the project than by their communities (Duncan 2017, p.445). This implies that community members should not be part of the co-production team (Duncan 2017). However, another perspective is that this situation reflects the boundaries imposed on community members by those ‘in charge’. In true co-production, participants should be free to express their community’s views. Community division would not be a consequence of a genuinely co-produced project if representatives could authentically represent their community’s views. Additionally, concerns about co-production leading to “reputational damage” (Cooke et al. 2021, p.250), a point not elaborated upon by the authors, might also make knowledge producers and brokers hesitant to integrate lived experience knowledge as evidence due to potential (perhaps unwarranted) fears.

While less prevalent, some literature focuses on the co-production of knowledge mobilisation rather than knowledge production, which holds greater relevance for the current project. This aspect falls under ‘capacity building’, where co-production between researchers, policy

makers, and practitioners is suggested to make research knowledge “more actionable” (Heiskanen et al. 2014, p.30). This claim is supported by the notion that including knowledge users in the knowledge mobilisation process helps determine which research is locally relevant (Lamont and Maxwell 2023). Furthermore, it is recommended that knowledge brokering teams should be “composed of people with different professional backgrounds” (Kislov et al. 2017, p.110). This diversity is often achieved within specific KBOs, whose teams commonly consist of academics and individuals with public and/or private sector experience (MacKillop et al. 2023). However, it is also suggested that people with lived experience – ‘service users’ – could be involved in knowledge-brokering processes, not just in producing knowledge (Boivin et al. 2014). There is potential for knowledge brokers to engage more actively in co-production (Gough 2020), including playing a facilitative role by utilising their expertise to foster strong relationships among various actors (Beckett et al. 2018; Cooke et al. 2021). Such facilitation could expand into capacity-building for those with lived experience to act as knowledge brokers for their communities, (e.g., Henderson and Kendall 2011), which could benefit policy making, potentially improving the uptake of policy initiatives within the community through this alternative form of boundary spanning.

Who gets a seat at the table?

Arguably, the most important issue in co-production, transferable to the inclusion of lived experience knowledge as evidence, is determining who gets a seat at the tables of knowledge production, synthesis, and utilisation. It is argued that citizens, especially those with lived experience, can democratise knowledge production and shift perspectives on what is considered ‘evidence’. However, these claims are often undermined by the exclusion of certain individuals through restrictive recruitment criteria or by creating a hierarchy of more or less legitimate voices.

The KBO and policy making literatures do not consistently conceptualise co-production as inclusive of the lived experience voice. Indeed, while few definitions are explicitly provided, Neal et al.’s (2023) definition suggests the exclusion of service users – people with lived experience:

“We also define knowledge producers as those individuals or organizations involved in the creation of research evidence (e.g., researchers; research institutes) and knowledge users as individuals or organizations whose decision-making is informed by research evidence (e.g., practitioners, policy makers, non-profit organizations).”
(p.4)

People with lived experience are those who will be most affected by changes to policy, and in Wales, they are expected to have a seat at the table. However, even when lived experience voices are included, there are questions about “who gets to be in the room” (Beresford 2019; Exley 2021, p.9).

There is debate over the perceived legitimacy of citizens recruited for co-produced projects (Boivin et al. 2014). Some expect citizen members to meet criteria similar to those used by KBOs, such as the ability to work collaboratively, be “consensus-seeking”, remain objective and independent (Duncan 2017, p.445), and communicate information clearly and succinctly (Sanders 2023). Others describe recruiting citizen members as a matter of convenience, often selecting individuals they have previously worked with (Juri et al. 2022). More unusually, some projects democratically choose their lived experience representatives (Henderson and Kendall 2011). These recruitment methods suggest that often, even when involving people with lived experience, the ‘usual suspects’ are included, while those from more marginalised communities, who might provide dissenting voices, are excluded (Duncan 2017; Beresford 2019).

There is an acknowledgement of a lack of divergent voices in co-production (Juri et al. 2022), especially relevant considering those often excluded are from minoritised groups (Beresford 2019). For instance, people from minoritised ethnicities are often “sidelined”, a trend observed in multiple countries and policy contexts (Elvy 2014 cited in Alnabilsy and Levin 2023, p.2). Greater effort is needed to include indigenous communities and other minoritised ethnicities (Juri et al. 2022). Women, too, face barriers to participation, or when included, find their input is not listened to (Alnabilsy and Levin 2023). Of particular interest to the current project is the exclusion of disabled people (Beresford 2019). According to Beresford, the reasons for this exclusion are threefold: presumed incompetence, where it is assumed based on impairment type that inclusion is “too complex”; communication barriers, especially for members of the D/deaf communities; and fear of dissent leading to “unwanted voices”, with examples often including neurodivergent people and those with dementia (p.9).

The question of who is given a seat at the table for contributing knowledge and evidence in policy making can either create or mitigate competition and tensions between different equality groups (Sanders 2023). However, instead of fostering an environment where representatives of different equality groups feel they are competing for a single seat (Sanders 2023), it might be more beneficial to enlarge the table to ensure there are seats for those not usually invited (Wibeck et al. 2022).

Methods

Approach

We undertook semi-structured interviews and documentary analysis. While interviews are a suitable method for collecting data on people's opinions and experiences, it is important to note that these data are what participants are willing to share with a researcher and are mutually constructed during the interview process (Frey 2020). Furthermore, documents produced for public consumption are often carefully crafted, presenting information that the author intends for the reader. However, this study focuses on how lived experience evidence and co-production for disability policy making are discussed and conceptualised, rather than asserting an 'objective truth'. By paying attention to the discourses constructed by both interview participants and document authors, we explored how knowledge brokering organisations, grassroots organisations, and Welsh Government conceptualise lived experience evidence and co-production, as well as their role in evidence gathering for disability policy making in Wales.

Population

The study aimed to interview participants working in disability grassroots organisations (GROs) who had contributed to Welsh disability policy making, individuals in KBOs who had provided evidence to inform Welsh disability policy making, and employees of the Welsh Government, such as civil servants, involved in the Welsh disability policy making process.

Ethical approval for this study was granted by Cardiff University Business School, SREC reference 2153.

Few KBOs explicitly identify themselves as such. To determine inclusion in the study, we used criteria derived from MacKillop et al.'s (2023) description of the key features of KBOs and constructed a matrix to score potential KBOs. This matrix was based on self-authored descriptions of their work and their employees' experience published on their websites (Table 1). Potential KBOs were identified by screening reports, implementation frameworks, and evaluations generated for Welsh Government related to disability policy, looking for any mention of involvement from external agencies. GROs were defined as organisations run by members of the group they represent – in this case, disabled people – whose primary function is systems advocacy to improve the lives of those they represent. It is noteworthy that many GROs perform similar functions to KBOs, including knowledge synthesis for policy making. This parameter was defined before recruiting interview participants and conducting document searches.

Interestingly, few references to KBOs were found in policy documents and reports related to disability published by Welsh Government. In fact, many of the screened policy documents and reports did not mention the involvement of external knowledge brokers. Often, the work was conducted in-house, alongside lived-experience advisors and third-sector organisations such as Disabled People’s Organisations. The few organisations that were mentioned were added to the matrix to ascertain their “closeness” to the concept of a KBO, in order to determine which organisations would be suitable to approach for participation in this project.

Table 1 – KBO Matrix and Organisational Score

Point	Maximum score	KBO 1	KBO 2
Evidence and evidence-informed policy making are central to their work (sole function, or a main function).	2	1	2
Boundary spanning: <ul style="list-style-type: none"> • Tools and processes (e.g., evidence syntheses, data analysis) • Relationships (policy, research, and practice) • Diverse teams (academics, civil servants, third sector and private sector) 	3	3	3
Government funded, directly or indirectly through grants.	1	1	1

Emails containing participant information sheets and consent forms were sent to employees from the shortlisted organisations. These were sent either directly to individuals or to team mailboxes, for example, the Welsh Government Disability Disparity Evidence Unit. This approach resulted in seven interviews (KBO n=2, GRO n=2, Welsh Government n=3).

Interviews

An interview guide, featuring sample questions and discussion topics, was sent to all participants before their interviews. The interviews were conducted and recorded using Zoom, lasting between 34 and 71 minutes. Each interview began by asking the participant about their process for gathering evidence for policy making. Subsequent questions focused on the inclusion of lived experience evidence before shifting to co-production and the integration of different forms of evidence. One interview was conducted via email.

Interviews were transcribed shortly after their conclusion, and the transcripts were immediately pseudonymised. Transcripts were reviewed while listening to the audio recordings, with annotations indicating where participants stressed particular words or phrases.

Documents

We conducted a systematic approach to locate appropriate documents for analysis using the following inclusion criteria:

- Produced by an involved KBO/GRO and/or;
- Produced for – and published by – Welsh Government and;
- Write about co-production for policy making and/or;
- Write about lived experience for policy making and/or;
- Provides examples of co-production for policy making and/or;
- Provides examples of lived experience evidence for policy making.

Documents were excluded if they:

- Were not produced by an involved KBO/GRO and/or;
- Were not produced for – or published by – Welsh Government and;
- Did not focus on disabled people (e.g., focused on carers) and/or;
- Had less than one paragraph about co-production for policy making and/or;
- Had less than one paragraph about lived experience for policy making and/or;
- Mentioned co-production and/or lived experience specifically in relation to practice and/or;
- Were not publicly accessible.

‘Policy’ encompasses various forms, including Codes of Practice, Frameworks, Implementation Plans, Bills, Acts, Strategic Action Plans, and Inquiries that inform policy makers. Consequently, all these forms were included under the ‘policy making’ umbrella for this study.

A search for publicly accessible documents (including reports, written statements, webpages, etc.) produced by Welsh Government and all organisations that had agreed to be interviewed was conducted using broad terms such as ‘disabled’, ‘disability’, ‘co-production’, and ‘lived

experience' (n=236). Titles and introductions were screened for relevance, and all potentially relevant documents were downloaded for full-text screening (n=41). This screening closely examined how co-production and lived experience were presented, paying particular attention to whether these were mentioned specifically in relation to policy making. Documents were excluded if they mentioned co-production and/or lived experience solely in the context of practice or research (n=13); were mere examples of co-produced policy without elaboration on the process (n=2); were literature reviews (n=1); excluded disabled people from lived experience (n=1); or were unrelated to policy making (n=1). Twenty-three documents were ultimately included in the analysis (Appendix 1).

Of the twenty-three documents analysed, only two were co-produced with disabled people.

Analysis

All documents and transcripts were uploaded to NVivo12 for analysis. Data were analysed using Braun and Clarke's (2022) six-phase reflexive thematic analysis. This involved familiarisation through repeated reading of the data; coding with a focus on how co-production and lived experience were discussed rather than just semantic content; generating initial themes from the codes; developing and reviewing themes across the dataset; naming themes; and writing up the analysis.

As the documents varied in focus, not all contained data addressing each research question. Consequently, the constructed themes do not represent a consensus nor are they drawn from all data items. For example, only 13 items contained data related to the theme of porous boundaries. While this does not diminish the richness of the data, it could be considered a limitation of the study. The following section presents the themes and sub-themes derived from the analysis.

Findings

Porous boundaries

The data indicates that some concepts from the literature do not have fixed definitions. It also demonstrates that concepts with varying definitions are sometimes used interchangeably or conflated. For instance, disability policy making might exclusively concern policies related to disabled people. Conversely, it could also encompass how general policy affects disabled people, where there are “no clear boundaries” (Knowledge Broker 2). As one participant noted, disabled people “don’t live in bubbles” (Grassroots 1).

Co-production and lived experience evidence are generally understood as separate concepts. Co-production is often described as a process or approach to include people in an equal partnership, for example, to engage in “joint agenda-setting” (Heath and Mormina 2022, p.1708) or decision-making. Lived experience evidence is typically described as knowledge or information from individuals who have personal experience of a topic. In disability policy making, this frequently refers to disabled people. However, some also include disabled people's parents or carers in this definition.

“[...] there’s quite a distinction between research that involves lived experience [...] and presenting that lived experience and including that in a report [...] and kind of co-production” (Knowledge Broker 2).

For some of those interviewed, lived experience evidence is “just good qualitative research” (Knowledge Broker 2). For others, lived experience is separate from qualitative research:

“We do qual and quant research as well. But that’s [...] slightly separate” (Welsh Government 1).

Documents and interviewees also often discussed co-production and lived experience interchangeably. Other times, co-production and lived experience evidence were treated as inseparable:

“[...] develop our use and understanding of lived experience by establishing a co-production approach” (Document WG28)

**“[...] you can’t really have co-production without lived experience”
(Grassroots 2)**

This suggests that while people may use the same terms, they sometimes attribute different meanings to them. Without agreed definitions, it can be challenging for people with lived experience to understand the subject matter. For everyone involved, there is a lack of clarity about what is included when evidence and policy claim to be informed by lived experience. This implies that it is important to consider not only how literal differences in language and culture can create barriers to the inclusion of people with lived experience, as discussed in Alnabilsy and Levin (2023), but also exclusionary institutional language practices and cultures.

Knowledge brokering organisations and grassroots organisations are typically understood to have different roles in the evidence-for-policy process (MacKillop et al. 2023). However, the way interviewees described their work suggests that the boundaries between these roles are porous. For example, grassroots organisations often perform functions akin to knowledge brokers, conducting “background research” (Grassroots 1) and acting as a “funnel” (Grassroots 2) to provide evidence to policy makers.

The data also reveals that knowledge brokers can describe their work using the language of grassroots organisations, such as engaging in ‘advocacy’:

“I guess from an advocacy perspective, the main thing that if [lived experience evidence] helps with is to really demonstrate the impact of things” (Knowledge Broker 1).

This challenges the notion that knowledge broker organisations are distinct from other types of organisations, suggesting that their differences are ‘constructed’ rather than ‘real’ (see MacKillop et al. 2023).

The literature often portrays people with lived experience, policy makers, knowledge brokers, and grassroots organisations as distinct groups, with little acknowledgement of potential overlaps. However, the interviews and documents show that sometimes policy makers and grassroots organisations are also people with lived experience:

“[...] we’re a disabled people’s organisation our entire staff is disabled, all of our trustees are disabled [...]” (Grassroots 2).

**“I mentioned it briefly about [...] having lived experience in staffing”
(Welsh Government 1).**

However, this was occasionally discussed in a way that substituted people from grassroots organisations for those who could be considered ‘lay’ individuals with lived experience. This was linked to the idea that merely being a person with lived experience is insufficient; they also need to understand how policy functions to effect positive change within policy making:

**“[...] you don’t just need lived experience you need to be able to
understand policy [...]” (Grassroots 1).**

This conflation of grassroots organisations with lived experience raises questions about hierarchies and power, including the notion of the expert as discussed in the literature. Interviewees and documents viewed grassroots organisations as providers of both lived experience evidence and policy knowledge, positioning them as “super experts” (Welsh Government 2). This also implies that other people with lived experience are not regarded as experts and can be excluded.

The manner in which different groups are discussed can influence their legitimacy as knowledge producers, as explored in literature on lived experience evidence from individuals with mental illness (Rose and Kalathil 2019). This concept of lay lived experience being distinct from expertise was evident throughout the interviews and documents. For example, an “expert clinical group” was mentioned alongside “a wider stakeholder group” that included people with lived experience (Document WG33). While it is accurate to acknowledge distinctions between different types of knowledge, it becomes problematic when this distinction implies that one type of knowledge is more valid than another.

What evidence matters?

Lived experience is seldom explicitly described as evidence, with many data sources treating it as separate from evidence. However, the way some documents referred to “evidence voiced” (Document WG4) by people with lived experience suggests a recognition of its validity as a form of evidence. Some interviews and documents described lived experience as “essential” (Grassroots 1), “vital” (Grassroots 2), and “incredibly valid” (Welsh Government 1). One document highlighted the statutory duty to include lived experience, demonstrating the importance of lived experience to disability policy making:

“The guidance stresses the need for public bodies to consider lived experience when making strategic decisions” (Document WG27).

However, there is some suggestion that lived experience might be too individual and therefore might not cover what is needed for all disabled people:

“[...] individuals are experts in their own lives and sometimes there is a limitation with that” (Welsh Government 2).

There were concerns that lived experience evidence might “not necessarily be fully applicable to [the] full population” (Grassroots 2). This concern was sometimes expressed using terms like “skewed” and questioning its “validity”. This suggests that quality measures for quantitative studies, which typically top the traditional evidence hierarchy (Smith-Merry 2020), are being granted more authority than qualitative quality measures like credibility, transferability, dependability, and confirmability (see Bryman 2016, p.44). It also raises the possibility that lived experience evidence may not meet those qualitative measures, such as being non-transferable beyond the individual.

Moreover, lived experience was often not described as evidence in the documents and interviews, but rather as something distinct from traditional evidence and the “true picture” provided by “statistical input” (Document WG27). This is notable, considering the need for information to be accepted as evidence by policy makers (MacKillop et al. 2023). Even where lived experience evidence plays an important role in informing policy, more traditional forms of evidence were often seen as the “gold standard” (Knowledge Broker 2) for policy evaluation. Concerns about the “bias” (Grassroots 1) and “objectivity” (Document WG28) of lived experience evidence echo literature that places quantitative studies above qualitative studies, and both above lived experience, in the evidence hierarchy (Rose and Kalathil 2019; Isett and Hicks 2020).

However, not everyone concurred with this hierarchy. Some interviewees emphasised the need to ensure that lived experience “receives parity with ... qualitative and quantitative analysis” (Welsh Government 1) while others said that they “don’t see quantitative research as neutral” (Grassroots 2). These viewpoints align with literature recognising the value of tacit knowledge as evidence (Ward et al. 2009; Best and Holmes 2010) and questioning the objectivity of traditional research knowledge (e.g., Greenhalgh and Wieringa 2011).

Interviews and documents also highlighted the challenge of balancing power dynamics in the knowledge production process. Some noted that policy makers still exert control over which lived experience stories are included as evidence:

“[...] it’s about who is making those decisions where the power lies [...]” (Grassroots 2).

This could be problematic in cases where evidence from people with lived experience is considered to be “criticism” from “troublemakers” (Grassroots 1). This situation aligns with literature suggesting that those in power decide what constitutes “legitimate” evidence (Exley 2021, p.9) or is “policed” (Rose and Kalathil 2019, p.5). The power to validate or invalidate citizen knowledge, particularly among disabled citizens, is a recurring theme in literature (e.g., Beresford 2019; den Houting et al. 2021). Interviews and documents propose that a co-productive approach to generating, and sometimes synthesising and integrating, evidence, where power is shared among policy makers, knowledge brokers, practitioners, and people with lived experience, could mitigate this issue.

However, some knowledge brokers can be concerned with “not putting lived experience on a pedestal” (Knowledge Broker 2), while questioning “how equal” (Knowledge Broker 2) power-sharing should be.

Policy makers also play a role in deciding who contributes their lived experience. They inform people about projects using mailing lists:

“You need to be signed up to Welsh Government or Health Board mailing lists to get that information” (Grassroots 1).

This means that often the same “already active” individuals (Welsh Government 2) contribute their lived experience. It was suggested that the ‘usual suspects’ involved in disability policy making comprise those highly engaged with grassroots organisations, Welsh Government groups, and services.

Documents and interviewees acknowledged issues of intersectionality and “[recognise] that many disabled people have multiple protected characteristics” (Document DW1). Despite this awareness, some individuals – particularly those from minoritised ethnicities or with learning disabilities – are inadvertently excluded from providing lived experience:

“[...] people who have a learning disability are certainly excluded [...] sometimes their leaders come along but they often don’t come along with people who are learning disabled” (Welsh Government 2).

Interviews and documents suggest that some people are excluded because they do not trust researchers and policy makers:

“[...] there was that whole narrative of not having any trust in institutional processes [...] not wanting to participate because of their past experience of marginalisation and oftentimes explicit racism [...]” (Knowledge Broker 1)

This lack of trust that people with lived experience have towards policy makers and others in the policy making process, along with the resulting barriers to their inclusion in providing evidence, speaks to the issue of whose evidence is valued. The question of who gets a seat at the table, raised in current literature (Beresford 2019; Exley 2021), and both the literature and the documents and interviews suggest that more needs to be done to ensure a diversity of voices are heard. Wibeck et al. (2022) argue for a larger table, but there also needs to be a concerted effort to address the lack of trust from particular lived experience groups. One area that must be addressed are trust issues resulting from previous tokenistic involvement or being “treated as a bit of an afterthought” (Grassroots 2) in the policy making process. Furthermore, the way projects are advertised must be reviewed to ensure currently excluded groups are included in future initiatives.

Evidence integration and co-production

Interviewees and some documents emphasised the importance of lived experience evidence. However, they also acknowledged the significance of other types of evidence being important for good policy making, and that lived experience evidence is “one of the tools in your toolkit” (Knowledge Broker 2). Therefore, using a variety of evidence types to address policy makers' questions is important.

Nonetheless, few documents describe how they integrate different types of evidence, and some interviewees seemed to find the question quite difficult to answer:

“I think figuring out how we reflect lived experience alongside quantitative and qualitative evidence, we haven't quite figured that out yet so it's difficult for me to answer” (Welsh Government 1).

Some individuals mentioned looking for repeated patterns in their data. Others compared the process to mixed methods research projects, considering lived experience as “an integral part of good qualitative evidence” and that the different evidence needs “triangulation”:

“[...] there’s obviously broadly a lot of literature around mixed methods approaches [...] there’s nothing about lived experience research that means that is not applicable [...] a key part is triangulating different sources of data [...]” (Knowledge Broker 2)

Triangulation, according to the data, might also counteract any perceived limitations of lived experience evidence, particularly concerns about it being too individual, as discussed above:

“There are no limitations if lived experience is used alongside other forms of evidence collection, where required.” (Welsh Government 3)

Triangulation is a technique used in quantitative, qualitative, and mixed-methods research and is believed to enable “greater confidence in findings” (Bryman 2016, p.386). Rather than subscribing to the current debates over the validity of traditional evidence versus lived experience evidence, the documents and interviews suggest that integrating multiple evidence forms enhances legitimacy. For example, relying solely on quantitative data, “you are going to miss that nuance [from lived experience]” (Grassroots 2).

Triangulation and evidence synthesis can involve people with lived experience in a co-productive way, as evidenced in Welsh Government disability policy making. Here, triangulation and evidence integration are conducted by co-produced “working groups” (Welsh Government 3). Documents and interviewees stressed that co-production is essential to good “robust” (Welsh Government 1) policy making, as it strengthens both the evidence base and the resulting policy. As one document states:

“Lasting change is not created by lone heroes” (Document AUK1).

Among the interviewees and documents discussing which stages of policy making should be co-produced, almost all indicated that it should occur at every stage. Co-production was frequently emphasised as being particularly important at the beginning of the process, implying that current practices are limited when they include people with lived experience only after the policy agenda has been set:

“The co-production should be right at the beginning if possible, it should be the very early stage of formulation, the later it comes the harder it is for people to do any good” (Welsh Government 2).

However, there appears to be a distinction between an expert and a person with lived experience, which is important to consider for co-produced policy making. Documents and interviews suggest that some elements are too “technical” for people with lived experience, indicating a lack of consensus on whether co-production should be involved at every stage:

“[...] if research is highly technical, we will invite involvement in other ways [...]” (Document WG28).

It is also not clear what people mean when they talk about co-production. While some documents provide detailed explanations, such as stating that “co-production is underpinned by 5 principles” before listing them (Document WG23), most documents included in this study did not offer such comprehensive definitions. Others acknowledged that they were just “starting to describe what co-production looks like” (Document WG28). Some interviewees struggled to define the concept, saying that co-production made them feel “nervous” because “co-production is one of those things that’s always felt a rather slippery concept, a bit nebulous” (Knowledge Broker 2). Some interviewees said that “true co-production is ... involving people with lived experience” (Welsh Government 1). This description of co-production is one that aims to share power as “equal partners” (Welsh Government 1) and to “break down ‘them and us’ attitudes” (Document AUK1).

The absence of a single definition of co-production reflects the current literature. However, descriptions of co-production as an equal partnership that breaks down boundaries resonate with descriptions of co-production as a democratising process (Juri et al. 2022). Moreover, the documents and interviews support literature suggesting that co-production can improve policy making outcomes (Duncan 2017; Beckett et al. 2018). To ensure everyone involved has a consistent understanding, agreeing on a definition of co-production is crucial to avoid differing interpretations of concepts (see Culwick et al. 2019). Only when people use the same language can truly democratic, power-balancing co-production occur.

However, some interviewees expressed that it is challenging for people with lived experience to be truly equal partners. This difficulty partly stems from the endpoint of co-production, where Ministers make the final policy decision. It was noted that “the government is the one that’s ultimately responsible” and there cannot be equal partnership where there is not equal responsibility “if it all goes wrong” (Welsh Government 2). Co-production also depends on all parties agreeing to, and adhering to, an equal partnership. However, this equal partnership is

not always realised in practice, leading to feelings of exclusion among people with lived experience. The discourse around the lack of adherence to equality in participation typically referred to other participants in co-production, rather than Welsh Government officials or people with lived experience:

“Many expressed the view that it was not necessarily the attitude and commitment of Welsh government to disabled people, but the attitudes, inactions and exclusionary behaviour of other public agencies [...]” (Document WG4).

Even though co-production is seen as important, many consider it, along with lived experience evidence, to be resource-intensive and more time-consuming than methods that omit these elements. When participants consider the differences between the type of co-production they currently undertake and what they would consider as ‘true’ co-production, a lack of time combined with external pressure to get work completed on time was cited as a reason that they sometimes cannot work in a fully co-productive way:

“[...] it will run up against time [...] just not [...] practically logistically. Anything that’s more difficult to do, just that’s not essential. There’s a danger that just won’t happen” (Knowledge Broker 2).

However, a counterargument is that including people with lived experience at the earliest stages of policy making reduces the likelihood of “glaring errors” (Grassroots 2) in policies that result from not considering the needs of disabled people. Errors, which “could have been sorted very very quickly” (Grassroots 2) if disabled people were consulted, suggest that despite the apparent resource-intensive nature of this approach, it can ultimately save time and money:

“[...] if we don’t use that lived experience that actually it can be a waste of money a waste of resources because we’re then designing things that we assume that people want, and that we assume that people need [...]” (Grassroots 1).

Despite the barriers to co-production identified in the data, none of the sources suggested that co-production might lead to the “reputational damage” as proposed by Cooke et al. (2021). Indeed, the greatest barriers to true co-production are time and resources, as also

discussed in current literature (Duncan 2017; Beresford 2019; Rose and Kalathil 2019; Richards and Scowcroft 2020). However, both the literature and the data from this study suggest that co-production can enhance the usability of evidence for policy making (Heiskanen et al. 2014; Lamont and Maxwell 2023), potentially saving time and resources. Therefore, while it is important that time and cost are factored in to ensure that true co-production is sustainable, the potential savings from higher quality evidence and syntheses for policy making should also be factored into these calculations.

Conclusion

Disability policy making in Wales necessitates the inclusion of people with lived experience, encompassing both lived experience evidence and co-production. This requirement potentially explains why some participants and documents conflate these terms. Despite the significance of lived experience, references to its inclusion in the knowledge-brokering literature are scarce, with some mention of the co-production of knowledge mobilisation but not in relation to disability policy making.

This project seeks to fill this gap in the literature by examining lived experience evidence and co-production in Welsh disability policy making, as perceived by grassroots organisations, KBOs, and Welsh Government. Through semi-structured interviews and document analysis, we investigated how boundaries that might be considered distinct, are discussed in ways that render them porous. This could lead to misunderstandings if people, despite using the same words, do not share the same understanding. Such misunderstandings could result in people with lived experience being excluded due to institutional language practices. Porous boundaries might also mean that lay lived evidence is delegitimised in favour of the “super expert” people with lived experience from grassroots organisations.

We also examined what evidence is considered important, and how lived experience evidence is afforded varying degrees of validity compared to traditional evidence. This analysis revealed power imbalances in knowledge production and synthesis, especially regarding who decides what is included as evidence and who is excluded from lived experience evidence, such as people from minoritised ethnicities and people with a learning disability.

Finally, we explored evidence integration and co-production. Participants often found integration challenging to articulate but frequently viewed it as a method for triangulating data or akin to mixed methods research. Discussions underscored the importance of using multiple evidence sources for policy making. Interviewees and documents also discussed how this work could be conducted co-productively, emphasising co-production at every stage of the policy making process. Despite being resource-intensive, participants argued that co-production could ultimately save time and money in the long term.

Author's recommendations

Several recommendations are proposed for policy makers and knowledge brokers:

- To ensure all parties are speaking the same language, it is crucial to define and agree on definitions for key concepts at the outset of any projects. Achieving this

clarity is important for making working practices and people's roles transparent, mitigating any confusion about the meanings of co-production and lived experience evidence. This approach will enable Welsh Government to meet its ambition of including lived experience evidence in policy making, while avoiding the inadvertent treatment of qualitative evidence from knowledge brokers as the lived experience voice.

- While including professionals with lived experience is important, providing space for lay people with lived experience facilitates a shift from representation to active citizenship. To address any concerns regarding the understanding of policy making processes, training can be offered to lay members who need it (Foster In progress).
- Lived experience evidence should be viewed as an essential part of robust policy making alongside other forms of evidence. Welsh Government's commitment to including lived experience evidence implies that it must be given the same validity as more traditional evidence forms. This also means acknowledging that, like all evidence forms, lived experience evidence has its limitations and benefits.
- To build trust with people with lived experience, policy makers and knowledge brokers should maintain transparency regarding power distribution. This is particularly crucial when considering who holds the power to accept or reject evidence.
- Efforts must be made to ensure that further marginalised groups are not excluded from providing lived experience evidence or participating in co-production. A key area of focus should be to avoid tokenistic involvement of people with lived experience in evidence-gathering and policy making processes.
- Evidence synthesis and policy making should be conducted in a co-productive manner. Any additional time and resources required should be factored into project budgets at their inception. The benefits of co-production in terms of producing accurate policy with the desired impact should be weighed against these time and cost resources.

Limitations

There are several limitations to this study that should be acknowledged. Most importantly, given the topic of the report, it is important to note that this project was not produced co-productively. While the author identifies as disabled and serves as a non-executive director of a grassroots organisation, this does not replace the involvement of lay lived experience. This omission was due to the project's short timescale of three months, which also constrained the number of interviews conducted, a further limitation of the study. Additionally, the project's scope was restricted to disability policy making within Wales, which may limit the applicability of the findings to other policy areas and jurisdictions.

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Appendix

Appendix 1 - Document properties

Document Code	Date	Organisation type	External author	Document type
AUK1	2023	GRO	No	Web page
AUK2	2023	GRO	No	Web page
DW1	2020	GRO	No	Manifesto
DW2	2020	GRO	No	Web page
DW3	2023	GRO	Yes - academic	Blog Post
WG10	2023	WG	No	Statement
WG11	2023	WG	No	Statement
WG13	2017	WG	No	Research report
WG19	2022	WG	No	Statement
WG2	2013	WG	No	Statement
WG20	2013	WG	No	Statement
WG21	2014	WG	No	Statement
WG22	2018	WG	No	Delivery or Action plan
WG23	2019	WG	No	Delivery or Action plan
WG24	2019	WG	No	Delivery or Action plan
WG27	2021	WG	No	Government response
WG28	2022	WG	No	Policy and strategy

WG29	2022	WG	No	Delivery or Action plan
WG30	2022	WG	No	Delivery or Action plan
WG32	2023	WG	No	Delivery or Action plan
WG33	2023	WG	No	Stakeholder feedback report
WG4	2021	WG	Yes - multiple org types	Research report
WG9	2022	WG	No	Statement

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