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The perspectives of agents working in positions of authority within health sector organisations regarding the involvement of experts by experience with an intellectual disability: An exploratory study

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ABSTRACT

Background: In this study, agents working in positions of authority within health sector organisations shared their perspectives concerning both the involvement of experts by experience with intellectual disabilities within their own organisations and their recommendations as to how best to involve experts by experience in policy and practice.

Method: Using purposive sampling, eight agents were selected for semi-structured interviews. The interviews were analysed using thematic analysis.

Results: The results indicated the importance of involving experts by experience. However, they also highlighted several barriers such as a lack of emphasis on genuine attention, insufficient visibility and recognition of expertise, and a lack of support for sustainable inclusion.

Conclusions: Agents are willing to involve experts by experience in health sector organisations, but practical challenges hindered them from actually doing so. This study emphasises the importance to find solutions for better inclusion in policies.

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Both in mental healthcare and the field of intellectual disabilities, the emergent interest in involving service users in care and support and taking into account their preferences, needs, and experiences, is grounded in political, philosophical, and societal critiques of the traditional biomedical model that emerged in the late 1960s (Millar et al., 2016; van Gennep, 2007). Consequently, in many countries, service users have become increasingly involved in their own care and support (Happell & Scholz, 2018), while, in turn, their experiential knowledge is valued and utilised to help optimise the quality of care and support provided to people with intellectual disabilities (Embregts et al., 2021). Within research and educational organisations, researchers and teachers are also increasingly collaborating with experts by experience with intellectual disabilities (e.g., co-researchers or co-teachers) (Embregts et al., 2021). This trend is predicated on the notion that in order to develop and exchange knowledge, the interaction between three types of knowledge sources is fundamental: scientific knowledge, professional knowledge (i.e., the knowledge of professionals), and experiential knowledge of experts by experience (i.e., the knowledge

of service users themselves as well as their relatives) (Garretsen et al., 2021).

An expert by experience is defined as “a person who, first, has particular experiential knowledge as a service user, and second, whose experiential knowledge is utilised in health and social care” (Toikko, 2016, p. 293). This knowledge can be applied at different levels, including the micro level (for individuals or small groups), the meso level (for facilities or communities), and the macro level (strategically or nationwide) (Castro et al., 2019). In our study, we focused on exploring the various roles that experts by experience with intellectual disabilities had within health sector organisations, such as employees, teachers, or advocates. The shift from comprehending one’s own experiences (experiential knowledge) to comprehending the experiences of a broader group of people (collective experiential knowledge) and effectively applying this accumulated experiential knowledge (= being an expert by experience) is a critical milestone in the process of becoming an expert by experience (Embregts & Frielink, 2023). It consists of four subsequent steps: (1) Identifying one’s own experiences (e.g., reflecting on personal experiences and

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preferences), (2) Understanding one's own experiences (e.g., recognising what is important and helpful), (3) Understanding the experiences of others (e.g., empathising with others' experiences and needs), and (4) Applying experiential knowledge to support and assist others based on one's own and others' experiences.

There is evidence from research that working with experts by experience within the health sector is associated with a multitude of positive effects. Specifically, support from experts by experience who have or had experience psychological problems can increase feelings of self-esteem (Verhaeghe et al., 2008), well-being (Bracke et al., 2008) and quality of life (Bouchard et al., 2010; van Gestel-Timmermans, 2011). Moreover, empowerment, hope and (self)confidence can also be enhanced through working together with experts by experience (van Gestel-Timmermans, 2011). Importantly, experts by experience themselves can also benefit from the support they offer to others (Grant et al., 2010; Solomon, 2004). For example, effectively helping others can induce feelings of gratitude, satisfaction, and recognition (Bouchard et al., 2010; Nestor & Galletly, 2008). Finally, working with experts by experience also positively impacts upon healthcare professionals, insofar as experts by experience can help to change the negative attitudes and social stigmatisation held by some professionals by virtue of showing themselves to be successfully people working in productive, recognisable social roles (Solomon, 2004).

Research exploring the care and support of people with intellectual disabilities, where the degree of involvement from experts by experience can range from an advisory capacity to a more collaborative approach based on partnership and equality, has also underscored the various benefits of working with experts by experience (Bigby et al., 2014). Specifically, experts by experience with intellectual disabilities can experience a sense of being valued (Bell & Mortimer, 2013; Nind & Vinha, 2014; van den Bogaard et al., 2023), being able to help others (Flood et al., 2013), and increased self-esteem and feelings of confidence, belonging, and reciprocity (den Boer et al., 2023; Flood et al., 2012; García Iriarte et al., 2014). Furthermore, Hall and Duperouzel (2011) reported that the involvement of experts by experience with intellectual disabilities in risk assessment had a positive effect on both the parties involved (i.e., increased awareness and knowledge) and their relationship with healthcare professionals (i.e., trustworthy collaborations).

Notwithstanding these aforementioned benefits, the structural involvement of experts by experience with

intellectual disabilities is often challenging in practice (Noorani, 2013). One reason for this is that organisations often face challenges in collaborating with experts by experience due to a lack of external guidance, financial resources, and specific strategies to facilitate their effective and meaningful involvement (McCutcheon & Gormley, 2014). As a result, organisations have to heavily rely on their internal knowledge and experiences to navigate the process of working with these experts. Moreover, although the prevailing assumption in mental healthcare research is that experts by experience are often still not fully involved in policy and practice due to continued stigma and a lack of strong leadership (Gurung et al., 2017), the perspectives of agents concerning the involvement of experts by experience with intellectual disabilities in policy and practice remains unknown. Focusing on agents working in positions of authority within health sector organisations is imperative in this respect, insofar as they play a pivotal role in terms of creating opportunities for experts by experience to become fully involved in both policy and practice. Consequently, this study aimed to explore agents' perspectives concerning the involvement of experts by experience with intellectual disabilities within their own organisations as well as their recommendations as to how best to involve experts by experience in policy and practice.

Method

Participants

The Ethics Review Board of Tilburg University granted permission to conduct this study (EC-2017.68r). Using purposive sampling, the authors contacted 10 agents working in positions of authority in health sector organisations, namely the Netherlands Ministry of Health, Welfare and Sport, a large healthcare organisation for people with intellectual disabilities, national advocacy organisations for people with disabilities, the Healthcare Inspectorate, the Dutch association of healthcare providers for people with disabilities, and a health insurer. The organisations were selected not based on their collaboration with experts by experience but because these organisations wield significant influence over the provision of care and support for people with intellectual disabilities. It is important to clarify that while most participants are from health sector organisations, the majority of these organisations were not primarily responsible for delivering services and supports to people with intellectual disabilities.

The authors provided these agents with background information on the study and requested their

cooperation to participate in an individual interview. Seven people initially agreed to take part and provided their written informed consent. As one of the participants also invited a colleague to participate, who subsequently also gave their written informed consent, a total of eight participants took part in this study; the two participants who worked at the same organisation were interviewed together. Hence, in total, seven interviews were conducted. The participants (five male) were an average age of 48.8 years (range 38–62 years) and had worked on average for 5.3 years in their current position (range 1–13 years).

Procedure

After the participants provided their written informed consent, an interview was scheduled at a convenient time and place for the participants; all of them opted to have the interview at their place of work. Each interview was conducted by the first author (an academic researcher) and the second author (a researcher with intellectual disabilities working as an expert by experience, who is hereafter referred to as the co-researcher). Prior to commencing the interview, the co-researcher explained the background to the study and both researchers provided information related to the confidentiality of the data they provided. The co-researcher then started the interview by posing the questions formulated in the interview guide (see section below). Both the co-researcher and the academic researcher asked open-ended follow-up questions related to the answers given by the participant. The interviews were conducted between 12 February and 4 March 2020. Each interview was audio recorded (average duration: 46 min; range 34–61 min) and transcribed verbatim. In addition, the co-researcher compiled notes immediately after each interview, where she summarised the answers that were given.

The interview guide

We opted to conduct semi-structured interviews focused on two aspects of the participants' experiences of working with experts by experience with intellectual disabilities. First, the participants' perspectives were explored with respect to the involvement of experts by experience in their own health sector organisations. For example, they were asked how experts by experience were currently incorporated into the vision and policy of their organisation. Second, the participants were asked for their recommendations on how best to involve experts by

experience within policy and practice. The complete interview guide is available upon request from the last author.

Data analysis

Following a thematic analysis framework (Terry et al., 2017), one researcher read through all of the transcripts to familiarise herself with the content, and then proceeded to inductively code the first three interviews. A second researcher then reviewed these initial codes, and the two researchers subsequently discussed the coding until they came to a consensus on the final coding schedule. Next, the last four interviews were coded based on this coding schedule by the same researcher. Subsequently, one researcher categorised all the codes into relevant themes, which was discussed with the entire research team until a consensus was achieved. To incorporate the perspective of the co-researcher into this categorisation process, the co-researcher first read back over the notes she had made after each interview. After this, the first author revealed an initial category and then invited the co-researcher to recall what the participants had said about it based on her notes. Her answers were logged and compared with the categorisation that had been agreed on previously by the entire research team. They also discussed the captions of each category to ensure that they fully encompassed the outcomes, which resulted in small adaptations being made to the categorisation. For example, following the co-researcher's valuable suggestion, we have rephrased specific observations using a more positive approach. Instead of simply mentioning the scarcity of time to develop and increase the involvement of experts by experience, the co-researcher recommended a constructive perspective, emphasising the importance of dedicating time to the gradual development and expansion of expert involvement. This adjustment effectively conveys the same message while offering an encouraging and inspiring tone. The definitive categorisation was discussed with all authors and the final results were then compiled.

Results

In the interviews, the participants gave (1) their perspectives concerning the involvement of experts by experience with intellectual disabilities in their own health sector organisations and (2) their recommendations on how best to involve experts by experience in policy and practice for people with intellectual disabilities.

The involvement of experts by experience with intellectual disabilities

The participants' experiences concerning the involvement of experts by experience with intellectual disabilities in their own organisations can be distinguished into several related topics: (1) Recognising the valuable input of experts by experience, (2) The need for guidance in navigating the role of experts by experience, and (3) Roles and compensation of experts by experience in organisations.

Beyond these three topics, it is important to first note that the respondents' interpretations of the concept of experts by experience itself differed, ranging from the experience a person possesses to the actual development of this ability to deploy one's own experiences for the good of others. According to the participants, such ambiguity over the concept itself runs the risk that requiring the physical attendance of an expert by experience becomes no more than an exercise in "tokenism" that does no real justice to the inclusion of their perspective. For example, as one participant put it:

It is not a sort of box-ticking exercise: 'Well, we have spoken with experts by experience. So now we're done. (R5)

Hence, developing a clear definition of the concept of experts by experience would provide better guidance concerning both what being an expert by experience actually entails and how best to involve these experts. This is critical given that the respondents perceived the lack of such a definition as hindering their efforts to involve experts by experience within their organisations.

Recognising the valuable input of experts by experience. The involvement of experts by experience with intellectual disabilities was generally endorsed by the participants. One important reason given by the agents for involving experts by experience is that they found their input to be essential for both understanding their "lived perception" and knowing what is actually relevant to service users and how to respond effectively. According to one of the participants:

If we don't understand what's happening there [amongst experts by experience and in the field], then we do the wrong things here [at the policy level]. (R6)

Alongside this, the participants also cited other reasons for involving experts by experience, namely: to contribute towards improving the quality of life of service users; to help fulfil the organisation's advocacy tasks; to improve the quality and relevance of their own policy or work; and to ensure that the perspectives of service users with intellectual disabilities are taken into account.

With respect to the latter goal, the participants underscored that service users' perspectives were brought more effectively to the fore when formulated by experts by experience themselves, as evidenced in the extract below:

I think those [previously mentioned themes] are themes we really look at, and we can discuss them ourselves with the organisation, but it hits home much harder through an expert by experience. (R2)

Interestingly, the participants indicated that there was no structural involvement of experts by experience in the form of formal employment within their organisations. In most instances, experts by experience were involved irregularly, and only recruited to participate in specific meetings or training sessions. The participants noted that they did consult and/or involve organised networks of experts by experience with intellectual disabilities or solicit service users' perspectives indirectly through healthcare professionals and/or relatives. Some of the participants stated that their organisations were seeking to involve experts by experience and formalise this aim within policy documents.

The need for guidance in navigating the role of experts by experience. Most of the participants stated that they were struggling with how to put the role and position of experts by experience with intellectual disabilities into practice within their organisation. They expressed a need for practical guidelines or concrete examples that they could adopt in their practice. According to some of the participants, the lack of such guidance made them more cautious regarding involving experts by experience, as they wanted to ensure that they effectively included them. An additional challenge cited by the participants pertained to the lack of manpower needed to provide the required support and assistance to experts by experience. Finally, some of the participants shared their proactive approach to involving experts by experience with intellectual disabilities, which included stepping outside of their comfort zone and making concerted efforts to embrace inclusivity. As the following statement reveals, this might pose challenges:

I also think it's very tempting to stay safely here in this building... You aren't asked many difficult questions... As soon as you stop doing that and go out into the field, then, yes, you expose yourself to all kinds of things which are far harder... Things you just don't always have answers to. (R6)

Roles and compensation of experts by experience in organisations. The participants stressed that there was a certain stratification in the deployment of experts by

experience, ranging from occupational activities to regular jobs, which, in turn, resulted in differences in the corresponding financial rewards, benefits and practical aids (e.g., laptops). As one participant put it,

Where do you make the distinction because that of course is what organisations frequently struggle with. It's often, so to speak, is this occupational activity or is it work? ... That's where difficult discussions arise, about when you think it should be a paid job for one person and when ... Sometimes that distinction is very clear, you know, because you see people who can add so much value that they're no different from someone who's on the payroll. But sometimes the distinction is harder to draw, and we struggle a bit with that, with: how do we deal with this? (R2)

Notably, within one of the advocacy organisations, the participating agent indicated that each individual with disabilities had the same working conditions as those without disabilities. Furthermore, the participants stressed that any payment to experts by experience might threaten the allowance they receive from the government. As a result, while most experts by experience express a preference for monetary compensation, they often opted to provide people with vouchers instead. The next obstacle cited by the participants with respect to the position of experts by experience within a care organisation concerned conflicts of interest:

Look, they're service users of ours. People we support. And at the same time they're also working as experts by experience, and sometimes employees as well. So you find yourself in a very ambiguous situation. That's what we have to deal with. (R1)

Hence, involving experts by experience within a care organisation for people with intellectual disabilities and utilising their experiential knowledge can serve to “change [the nature of the] relationships” with direct support staff:

So, you see, there's also a bit of stepping back as well. Many staff members are driven by their enthusiasm, but also to some extent by their belief that they know how things are and should be, that they're doing a job here. And now we suddenly say, 'Yes, but as well as your expertise there's also the expertise of experts by experience.' (R1)

Recommendations on how best to involve experts by experience in policy, care, and support for people with intellectual disabilities

While the participants acknowledged the importance of involving experts by experience in policy and practice for people with intellectual disabilities, they also indicated several barriers related to structurally involving

experts by experience (e.g., a lack of emphasis on genuine attention, insufficient visibility and recognition of expertise, and a lack of support for sustainable inclusion), which could be overcome by: (1) Shifting from economic values to embracing human values, (2) Elevating expertise and visibility of experts by experience, and (3) The importance of gradual developing the involvement of experts by experience.

Shifting from economic values to embracing human values. According to the participants, economic values are the predominant consideration, which, in turn, results in a focus on production, efficiency and finances. To structurally involve experts by experience, these values need to be replaced by more “human values,” such as “genuine attention and the human dimension” (R5). The participants also indicated that within the current work environment, it can be challenging to go off the beaten track. That is to say, they stressed that they often lacked the financial resources and courage needed to create the additional time and space to include experts by experience within policy, care, and support for people with intellectual disabilities. In the words of one participant:

But the trick is to dare to make room to do what adds value, so what you don't want is tightly defined projects with all kinds of frameworks and boxes to tick. You have to dare to make the time and the space to take a step to one side, if necessary, and to gather that knowledge gained from an expert by experience. (R8)

Elevating expertise and visibility of experts by experience. The participants noted that the expertise and knowledge possessed by experts by experience with intellectual disabilities is not necessarily seen as being equivalent to that held by people without intellectual disabilities. According to one of the participants, enhancing their visibility is an important factor in overcoming this issue:

You simply have to give them much more of a platform, and also start regarding them as experts, right? We don't do that enough, because very often what we do is hold a conference and invite a professor ... Right? Whilst in my view, the expert by experience has at least the status of a professor when it comes to things they have real experience with. I think that's really important. (R4)

In addition, participants indicated that enhancing the visibility of experts by experience with intellectual disabilities might be an important manner to change the perception of the general public; e.g., by using social and mass media and through role models in public organisations.

The importance of gradual developing the involvement of experts by experience. The importance of

taking time to gradually develop and increase the involvement of experts by experience, rather than, say, forcing the implementation of experts by experience in a top-down fashion, was stressed by some of the participants. Specifically, they noted that success should be celebrated, and that success depends on voluntariness, inspiration, and vision. They also underscored the importance of being willing to take time and create opportunities to involve experts by experience with intellectual disabilities within organisations:

Start here [at our own organisation], that's where we have something to learn. How can we make even more use of expertise of experts by experience in our own development of ideas, in our lobbying, in our standpoints. (R8)

However, they also stressed that they face several limitations in this regard, such as lacking the final responsibility or the necessary mandate within the organisation, albeit they acknowledged their own role in further encouraging both the inclusion and involving of experts by experience by addressing the issue publicly and stressing its importance:

Our task is to change the perception of people with intellectual disabilities. A disability is something people have, it's not what they are. (R4)

Discussion

In this study, agents working in positions of authority within health sector organisations were interviewed to gain insight into their perspectives on the involvement of experts by experience with intellectual disabilities within their own organisations. Moreover, they were also asked to provide recommendations on how best to involve experts by experience in policy and practice. The thematic analysis showed that the participants endorsed the involvement of experts by experience, emphasising, among other things, the value of experts by experience for understanding the perspectives of people with intellectual disabilities. However, the participants also indicated that there was no structural involvement of experts by experience in the form of formal employment within their organisations. In most instances, experts by experience were involved irregularly, and only recruited to participate in specific meetings or training sessions. Below, we will discuss key aspects related to agents' perspectives on involving experts by experience with intellectual disabilities within their own organisations, as well as their recommendations for effectively involving experts by experience in policy and practice for individuals with intellectual disabilities.

With respect to the involvement of experts by experience in their own organisations, various topics were addressed by the participants. First, the participants cited various reasons for involving experts by experience, including seeing their input as being essential for both understanding the “lived perception” of people with intellectual disabilities and contributing towards improving their quality of life. These reasons are in line with recent studies (e.g., van den Bogaard et al., 2023), which show that, from the point of view of principal investigators and academic researchers, one of the main reasons for working together with experts by experience – which in the case of van den Bogaard et al. (2023) involves being co-researchers within inclusive research projects – is the increased value and richness of the outcome for (clinical) practice and learning from each other's expertise in order to – eventually – contribute to an increased quality of life. Moreover, with respect to appointing experts by experience, the participants in this study noted that paying experts by experience might threaten the allowance they receive from the government, which, in turn, may evoke the feeling that their position in the workplace is not wholly equal to their colleagues without intellectual disabilities, at least in terms of appropriate payment arrangements. These financial issues have also been reported in previous research, particularly in the context of inclusive research (Frankena et al., 2019; O'Brien et al., 2022).

Furthermore, the participants called for more practical guidelines or concrete examples that they could subsequently adopt when working with experts by experience. Furthermore, they indicated that a lack of manpower negatively impacted upon their ability to provide the required support and assistance to experts by experience. Hence, this study shows that although the participants endorsed the involvement of experts by experience, the collaboration with experts by experience is far from self-evident. This finding is comparable to previous research, although it is important to stress here that there is a relative dearth of studies exploring the benefits of working as an expert by experience within the field of intellectual disabilities, while the limited studies that are available invariably focus on the benefits of deployment in inclusive research projects (den Boer et al., 2023). Within these inclusive research projects, collaborating together requires a range of competencies, such as communicating, being aware of skills and developmental needs, being aware of impact, and building a mutual relationship in which everyone involved can contribute (Embregts et al., 2018). In addition, collaborating with experts by experience requires time and critical reflection, which should be acknowledged and acted upon by health sector

organisations in order to create an environment in which experts by experience can contribute equally.

When asked about their recommendations to structurally involve experts by experience within policy and practice, the participants highlighted several barriers. These could be overcome by changing the prevailing mindset regarding the concept of experts by experience, shifting the focus from economic values to human values. In addition, taking time to gradually develop and increase the involvement of experts by experience and enhancing their visibility were also considered essential steps. The importance of visibility for people with intellectual disabilities in general has been emphasised in previous research, as increased visibility can lead to better prioritisation of this group in governmental policy and programmes and disability advocacy movements (Pelleboer-Gunnink et al., 2021a; Scior et al., 2016). Healthcare providers, public health policy, and agents in authoritative positions within health sector organisations play pivotal roles in these processes. An underlying assumption in the data was that experts by experience were viewed primarily as individuals contributing something valuable. However, in terms of recognition, building adequate and appropriate resources, and providing independent advice, disabled people's organisations (DPOs) and self-advocates have the potential to play a significant role in addressing the barriers identified by the research participants.

Increasing the visibility of the strengths and possibilities of people with intellectual disabilities is crucial, and self-advocacy, education, and enhanced intergroup contact can contribute to this goal (Dekker et al., 2022). Collective advocacy by people with intellectual disabilities can effectively demonstrate their capabilities within society, and sharing personal stories through various media platforms, such as books, television interviews, social media, and podcasts, can further enhance visibility. However, this endeavour requires sufficient resources, and the significance of advocacy groups should be widely recognised (Pelleboer-Gunnink et al., 2021a). Failing to acknowledge the strengths and possibilities of people with intellectual disabilities can lead to stigmatising attitudes, not only among the general population but also among mainstream professionals and colleagues (Pelleboer-Gunnink et al., 2017, 2021b; Voermans et al., 2021). This differential treatment can result in people with intellectual disabilities not being taken seriously, facing challenges in having their rights granted, and feeling dependent (Pelleboer-Gunnink et al., 2021b; Voermans et al., 2021). Consequently, the involvement of agents, particularly those in positions of authority, is crucial to effect positive change and bring about potential organisational cultural

changes. Previous studies have highlighted the pivotal role of agents in innovation and knowledge management processes, where they can influence their organisation's culture, including the acceptance and involvement of experts by experience with intellectual disabilities (Kersten et al., 2018). By embracing lived experiences and recognising the status of experts by experience, health sector organisations can foster a culture of inclusivity and value diverse perspectives (Embregts & Frielink, 2023). This shift in culture can lead to not only better integration of experts by experience with intellectual disabilities but also extend benefits to all employees within the organisation. An inclusive culture encourages meaningful participation and collaboration, promoting a sense of belonging and enhancing overall employee satisfaction and well-being (Lindsay et al., 2018).

A strength of our study lies in our commitment to foster an inclusive research environment, exemplified by the invaluable contributions of the co-researcher, who also works at the Dutch Self-Advocacy Federation by and for people with intellectual disabilities (LFB). Throughout the project, we ensured a positive and supportive atmosphere at the Academic Collaborative Center Living with an intellectual disability (Embregts, 2017), with our co-researcher receiving a full wage for her work at LFB and being seconded to our academic collaborative centre for 1.5 days a week to actively engage in various research projects. We maintained regular appointments several times a week involving her in every aspect of the study, engaging both the researcher and a dedicated coach to address any queries or concerns, thereby promoting open communication and collaboration. Nonetheless, the results of this study should be interpreted in light of some limitations. Firstly, while we acknowledge the consistent portrayal of the topic by the participants, the limited number of participants poses a constraint in our study. It is possible that other perspectives could emerge with a larger sample size. Moreover, as the study is qualitative, generalisability to a broader population should be approached with caution, particularly when applying the findings to different contexts. Future research would benefit from larger samples sizes to further strengthen the representativeness of the findings. Secondly, although having both an academic researcher and a co-researcher conducted the interviews is a strength of our study, it is important to note that the co-researcher did not directly code the interviews herself. Instead, the academic researcher handled the coding initially. Subsequently, the co-researcher assessed in meetings with the academic researcher whether the coding aligned with her understanding of the interviews and her reports

generated after each interview. This collaborative process allowed us to incorporate her unique perspective on the codes, informed by her notes taken during the interviews. In addition, the presence of the co-researcher during the interviews may have influenced socially desirable responses from participants. To address this concern, we took several measures during data collection to ensure the gathering of experiences related to both positive aspects and negative attitudes concerning lived experience expertise. The co-researcher, being an expert by experience, received extensive training in research ethics and qualitative data collection techniques to minimise framing bias in interview questions and create a comfortable environment for participants to freely express their perspectives. Additionally, the co-researcher established a strong rapport with the participants during the interviews, fostering openness and trust, encouraging the discussion of both positive and negative attitudes, as well as any concerns regarding experts by experience involvement. Thirdly, we used a purposive sampling technique – specifically, expert sampling – in which participants were chosen deliberately for the qualities they possess (Etikan et al., 2016). Related to this, the widespread reporting of irregular involvement of experts by experience by the participants may be considered a limitation of our study, and the perspectives of agents who do regularly involve experts by experience should be explored in future research. Finally, only agents working in positions of authority in health sector organisations were included. It would be interesting for future research to also explore the perspectives of both experts by experience themselves and the professionals who support them in their daily work as experts by experience (den Boer et al., 2023). Moreover, in future research, an intriguing avenue for exploration would involve focusing on the “human dimension” and its contrasting emphasis compared to “production, efficiency, and finances.” Understanding how this factor may exert diverse impacts at macro-, meso-, and micro-levels would add valuable insights to the literature.

In summary, this study indicates that agents are certainly willing to involve experts by experience in their organisations, but experience, among other things, practical challenges that hinder them from actually doing so. Collectively and through dialogue, all agents involved are called upon to continue to explore ways in which the involvement of experts by experience can be shaped within policy and practice, in order to discover additional new possibilities. This would constitute a clear step towards both the increased inclusion of, and participation by, people with intellectual disabilities and

designing policy and practice that positions service users as starting point.

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