MAT Of Medicine Anthropology Theory

SPECIAL SECTION

# Voicework and The Disarticulation of Young People's Mental Health Needs

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## Abstract

This article is about anthropological research ethics amid the simultaneous hypervaluation of young people's voices and the disarticulation (the process of making inarticulate) of their mental health needs. I reflect on my experience of recording a podcast about mental health treatment with young people in a moral context where 'voicework' was prominent. Following feminist critiques of 'voice' and 'choice', I argue that critical concerns usually associated with 'giving voice'—authenticity and empowerment—are limiting as means of ethically relating to needs, since they presume personhood rests on coherence, intentionality and articulate expression. Instead, I resolve to adopt a research ethics that focuses on articulating needs, rather than platforming voices. This account urges researchers—myself included—to do better in confronting the non-responsiveness of care systems.

# **Content Warning**

This article contains discussions of suicide, trauma, and inpatient abuse.

However, so as not to exclude readers who want to avoid this content, the concluding section, 'Moving Forward', summarises the argument without direct reference to these triggers.

# Keywords

Voice, Youth, Mental health, Research ethics, Care.

# Orientation

I have a dictaphone, kept, carefully, gingerly, never too far away. On it (or in it?) is the voice of a young woman, who, giggling, chose the pseudonym 'Hermione' to match her friend's 'Luna' (both characters from the Harry Potter novels). The recordings are over six hours of 18-year-old Hermione and Luna, Grace (a mental health worker) and I, recorded over several weeks, as we attempted to make a podcast together about equine-assisted therapy. We'd come to know each other well during my year of fieldwork at an equine-assisted therapy centre, where the two girls were longstanding clients. In fact, the recordings ended up being as much a critique of mental health treatment more generally as they were about what made the equine approach feel different. Both Luna and Hermione described desperation, disbelief and searing frustration in their experiences of not being helped. Whether in hospitals, schools, GPs or therapists' offices, or via application forms and infrastructural bureaucracy, too often they seemed unable to articulate themselves in a way that would prompt the provision of appropriate care. Everybody apparently wanted them to talk about their needs and feelings, but nobody was willing, or able, to actually respond to the things that they needed. The horses had acted as a salve. Their immediate responsiveness, and lack of requirement for verbal expression, was part of the appeal.

Hermione died by suicide, a few months after our series of recordings.

I didn't publish the podcast for a number of reasons, principally the impact that Hermione's voice might have on those who loved and missed her. In the months that followed, the dictaphone seemed to develop a new gravitational field, frequently drawing my thoughts and feelings to its small, black, plastic form. Those fragments of Hermione's voice preserved within it took on new weight. I wasn't going to platform that voice in the way we had intended, but I deeply wished I had responded differently to it.

This article is about the disarticulation (the process of making inarticulate) of young people's needs, at one and the same time as the hyper-valuation of their 'voices'. It is formed as a commentary on 'voicework' and ethnographic reflections on the making of those recordings. It also involves reflections on my own lack of response to the things I was told by Hermione and Luna. No doubt, this paper is in part a way for me to personally process the tragedy that has happened. But my hope is that it is also an opportunity to make an important critical observation about the way 'voice' is valued while response-ability (the capacity and imperative to respond; Haraway 2008, 88–93) is curtailed through the disarticulation at play in the provision of young people's mental health care. My story demonstrates an important distinction between, on the one hand, the metaphor of 'voice' as political representation (akin to vote, or choice, or 'say'); and on the other hand, the materiality of voices as interpersonal, dialogical, and often unclear, calls, cries, screams or whimpers that ought to invoke an immediate response. Both political representation and interpersonal utterances are important in the provision of care. and in the ethics of research, but my story urges people-myself included-to recognise that in this care context, while much attention is paid to political representation as a mechanism for begetting care, the capacity and imperative on listeners to respond to calls for help can be postponed, curtailed, deferred or diminished.

## A time of voicework

'How will you be including young people's voices?' 'How will you be engaging with service user's voices?' I have heard these questions, or iterations of them, in many guises, during my ethnographic research into equine-assisted therapies for young people in the UK. These questions had to be addressed during applications for research funding, in ethical clearance protocols, in responses to reviewers of publications, and in conversations with peers with similar research interests. This line of questioning was remarkably prominent, compared to other aspects of my political and ethical engagement in the field. Ethical accountability, for the early career medical anthropologist, seemed to be first and foremost a matter of voicework. I mean the term 'voicework', akin to 'culturespeak' (Hannerz 1999) to

refer to that sphere of labour that revolves around ensuring subordinate voices are heard, and critiquing whether or not they have been heard well enough.<sup>1</sup>

Anthropologists have often (in different times, in different places, in different ways) taken on the role of something like trailblazers in their interest in subordinate voices, standing against the dominant systems and listening out for the unheard and oppressed. My project sits at an intersection of two spheres of contemporary anthropology which both tend carefully, critically and valiantly to subordinate voices: childhood studies, and the anthropology of mental health. The anthropology of mental health has long attended to people's varied ways of understanding their own predicaments and treatments, and in different modes and mediums over time, it has persistently drawn attention to contrasts between those cultural or personal varieties and dominant (often Western, or biomedical) norms (e.g., Kleinman 1980, Frank 1995, Biehl 2013). In a similar vein, the anthropology of childhood has emphasised that children have their own meaningful perspectives on the world and engage as distinctive agents in complex social relationships, as opposed to merely functioning as adults-in-the-making (James 2007, Allerton 2016). The challenge of giving children a voice, as well as the importance of doing it, lies in the over-imposition of two parties-proximate adults, on the one hand, and dominant (e.g., 'Western', neoliberal, or white) voices, on the other, which can contribute to an intersectional predicament of marginalised children being spoken for. Research that can authentically empower or support children and young people is particularly challenging where the power distinction between researcher and subject also cuts across other important political distinctions, such as economic situation (Hoechner 2018), ethnicity (Ipe 2019), and criminality (Feixa 2023).

The imperative for anthropologists to critique dominant systems through giving voice to subordinates has felt increasingly urgent in recent years, amid growing recognition of the harms caused by the modern West, in relation to colonialism and climate change. But in the world outside academia, with growing force over the last two decades, an interest in subordinate voices has also itself become a dominant norm and a systemic practice, a matter of ethnographic interest and critical enquiry as well as a personal and professional concern for anthropologists, about how to do good research.

In my fieldwork, I found references to 'young people's voices' to be ubiquitous, in government documents, service guidelines, referral routes, mental health worker

<sup>&</sup>lt;sup>1</sup> This differs from the use of the term 'voicework' in musical therapy, where it refers to therapeutic ways of engaging voices as 'our most private and personal musical instrument' (Baker and Uhlig 2011, 25). Where differentiation is warranted, it may be helpful to refer to 'music therapy voicework' and 'critical voicework'—the latter relating to all of the work that goes into hearing the otherwise unheard voices, or critiquing the ways in which they are not yet heard correctly. Music therapy voicework is not completely distinct from critical voicework, the former could be seen as one species of the latter.

training sessions, at mental health conferences, and in interdisciplinary research agendas.

Practically, young people's voices carried utility because they could open doors, they could make things happen. For example, one equine-assisted therapy centre I studied won a substantial grant from a large private trust. Quotes from young people were part of the application. The grant offered not only money, but services in kind, including making a video about the charity. The filmmakers were keen to feature young people's voices. The final footage cut between head and shoulder shots of young people talking about their experiences, and slow-motion shots of the therapy horses overlayed with young people's voiceover. The film helped both the private trust and the therapy centre with their ongoing campaigns to build networks, garner legitimacy, raise profile, and enhance their reach. Young peoples' voices could do good.

This practical utility is in part thanks to the symbolic import that young service users' voices hold. Institutions—not just therapy centres, but schools and even states—can perform and enact progressive attitudes by giving voice to their young (Harris 2004). The voices of young people who are also deprived, black, female, disabled, or mentally ill hold particular value as beacons of justness and empowerment. Voicework with young people can seem to enact societal progression since the citizens of the future seem able to use their voices in the present, and in so doing, take the reins and drive forward change (Herrera 2014, Spyrou 2020). There's a counter to that too—for some conservative commentators, young people's voices can represent societal order gone topsytury, the tail wagging the dog, the spoilt and uninformed speaking out of turn. But even in this critical rendering, it is clear that young people's voices matter in contemporary society as a moralised symbol of change in the making (Cole and Durham 2008).

In addition to this symbolic value (indicating progress) and practical value (making things happen), young people's voices held importance to the therapists I worked with as a matter of ethico-political integrity during their direct interactions with young people (also, their 'goals': Jones McVey 2023). The epistemological politics of late modern Britain rendered a moral context in which elite status (white, middle-class, educated therapists) incurred a moral requirement for listening to those in less fortunate positions. It was conspicuous that ignorance was no (longer an) excuse for complicity in harmful political and social dynamics. For example, the 2017 #MeToo social media campaign had drawn public conscience towards not only the prevalence of sexual traumas and abuses suffered by young women, but also the shocking under-reporting and low conviction rate of sexual crimes. The moral response among the therapists I worked with was an increase in emphasis

on being 'trauma-informed' (e.g., in training sessions, supervisions, best-practice sharing talks), and a regular reassertion that young women must have space to be heard and believed. Similarly, the 2020 #BLM (Black Lives Matter) campaigns and protests heightened awareness, among the therapists that I studied, of their own white privilege and lack of knowledge or authority when it came to the racialised lives of many of the young people they worked with. In the midst of #BLM action, one of my field site therapy centres set up a reading group for therapists to learn more about the politics of race in relation to their own practices. In an ethical context of epistemological fragility and culpable ignorance, it was important to the therapists I worked with that they recognised the limits of their own authority, and remediated the power associated with their positions by foregrounding young people and service users' voices at every opportunity.

This ethos of mitigating one's own authority, and listening 'down', was not only important in the social context of mental health treatment, it was also instrumental in the logics and practices of the therapeutic modality itself. Therapy sessions usually involved watching and interacting with horses. In training, and in postsession debriefs, therapists supported one another in learning to speak less, and certainly to assert less, such that young people would create and voice their own descriptions of what was going on. They explained that young people should be the ones to describe whether, for example, a horse stamping his feet was missing its mother, having a tantrum, or trying to look cool. Young peoples' interpretations were taken as valid, meaningful, authoritative perspectives on the relationships they were engaged in. The aim was that young people could steer the therapeutic sessions towards their own concerns and needs, rather than following externally applied therapeutic aims associated with diagnostic criteria or therapists' sense of function and normalcy.

This equine-assisted therapy modality is one version of a much broader moral emphasis, within mental health care, on the individual as authority of their own predicament. Such an emphasis has a substantial and varied history, including humanistic approaches to talking therapy (often via Karl Jung and/or Carl Rogers); academic critiques of the institutional power of mental health treatment; and mental health survivors' movements. Since 2000, the NHS had been developing a model of 'person-centred care' which sets out to 'ensure that people's preferences, needs and values guide clinical decisions' (NHS England 2017). But patient voices had also become more important in the rising *critique* of state mental health services over the last two decades, amid devastatingly unmet needs (e.g., Children's Commissioner 2024, Young Minds 2023). Critical voices were not all of one type, some had emphasised the need for better access to medical care, while others had argued against the medicalisation of people's needs, experiences or behaviours (Speed 2006). In *children's* mental health care, an extra dimension was

the distinction between the children (as recipients/refusers of care) and their parents, carers, or teachers (who are often the instigators of/gate keepers to that care). In often being denied the capacity to define their own condition, Guro Parr Klyve describes children in mental health care as undergoing a 'double epistemic injustice' (2019).

Hence, my fieldwork took place in a context of youth services and mental health care that was replete with voicework. Voices were important (at least ostensibly), as the means through which treatments were arranged or demanded, delivered, evaluated and critiqued. While plenty of internal critique scrutinised the extent to which young people were *really* being heard, it appeared self-evident that to be properly cared for, one must first be properly heard, such that the political, ethical and economic problem of providing better care for young people was framed convincingly as a problem of 'listening' to their 'voices' as advocates of their predicaments. My aim is not to completely dismantle that framing, which in many contexts does good, but I want to draw attention to the power of that framing to obscure other questions of ethical import.

#### Equine-assisted therapy context

While this article isn't prominently about the therapeutic modality, a brief introduction to the equine therapy context may be helpful. Equine-assisted therapy is a growing phenomenon in the UK but also worldwide (particularly in the USA). Programmes vary in how they are situated in relation to more traditionally medicalised interventions. Qualification routes are varied, with some practitioners qualified in clinical psychology, psychotherapy, or counselling, but others coming from backgrounds in youth work, education, community work, or even more alternative routes such as 'energy healing': these do not all endorse one another. The setting featured in this article was staffed by clinical psychologists alongside specialists in equine care and management, and it took referrals from CAMHS and from specialist educational settings in order to work with young people who had diagnosed conditions including anxiety, depression, self-harm, suicidal ideation, eating disorder. OCD, and psychosis (a non-exhaustive list). However, the centre also offered 'equine-assisted learning' programmes alongside its therapy offer. Learning sessions were also supported by clinically trained staff, but had a larger service user-staff ratio. Referrals came from educational settings (including pupil referral units<sup>2</sup>), parents/carers, community settings, and other charities (such as a refugee support centre). Equine-assisted learning aimed to help young people with confidence, communication skills, empathy, anger management, teamwork, psycho-education, and trauma recovery. Some of the young people referred had

<sup>&</sup>lt;sup>2</sup> Pupil referral units cater for young people who are excluded from mainstream schooling, for medical or behavioural reasons.

diagnoses of autism, ADHD, pathological avoidance disorder, and/or PTSD (again, a non-exhaustive list). The funding picture for these services was complex—some young people's sessions were paid for by the local authority, for example, via education spending (such as education and healthcare plans (EHCPs)<sup>3</sup>), while others were covered by health commissioning. Still others were covered by particular pots of local or national funding, for example, for looked after children; or by referring charities (including a support charity linked to a local temple), or by the centre's own fundraising efforts—they were a charity, like most other equine-assisted therapy providers. The centre I worked at had become agile in finding funding routes for different young people that needed their help—but they were also all too aware of those who fell between the cracks and couldn't get funded access to their service.

#### Who can be heard? (And is that the right question?)

In 2021, amid the context of critical voicework described above, and amid the complex setting of an equine-assisted therapy and learning centre, I set about my own project of engaging with young people's voices.

I had decided recording a podcast was a good way to go. I could include young people in the planning and editing stages, and capture aspects of the tone and timbre of their voices which I felt I couldn't do justice to with my written words (see Woolner, this issue). I hoped the podcast provided a medium that was closer to the communicative mediums young people were likely to use themselves, and therefore, that they might be more able to express themselves comfortably, and engage actively in editorial decisions, compared to in a more mainstream academic medium of publication.

The next question was who to include. I ruled out those who were non-verbal, or who struggled with selective mutism. But how articulate should they be in order to be considered for inclusion in the podcast project? Some of the young people who I felt had the most interesting experiences of equine-assisted therapy would have been the most challenging to include. For example, 14-year-old Gulliver was extremely resistant to any dialogue or engagement with adults, but formed a seemingly positive relationship with a horse. He would likely not have been able, or willing, to articulate that relationship, since he rarely spoke to adults at all and when he did, I often read him as sarcastic, aggressive, or oppositional. I might have tried asking Gulliver if he wanted to be part of the podcast, but he always

<sup>&</sup>lt;sup>3</sup> EHCPs aim to provide for young people's health needs alongside their educational needs through bringing different sectors together. In reality, the EHCP system is so oversubscribed that it is in crises—both in terms of getting an EHCP and paying for its provisions (Sibieta and Snape 2024).

looked away, moved away, or glared, in order to deflect any sort of conversation from beginning.

Sam, a 17-year-old, was a possible candidate, as I felt we had a good rapport; he often asked to work with me as his volunteer-support when brushing horses. But his anxiety seemed to grasp him so completely that panic attacks could be brought on by the smallest degree of pressure. He apologised almost constantly, and he had expressed to his therapist that he felt he was persistently failing, letting people down, and making things complicated for others. He usually spoke in little more than a whisper, frequently pacing from foot to foot and wringing his hands around the back of his neck. Spending time with horses seemed to calm him, as long as somebody made it very clear they would ensure that the horses' needs were being met. The podcast could instil an additional worry and take away from the therapeutic benefits he received from being in a place that didn't over-test him.

While it seems important amid this ethnographic context to re-assert the point, it is already well established that voicework at the margins of inclusion inherently includes only a preferable selection of the most articulate, resilient, and wellsupported (e.g., Orner 1992). The staff at the centre clearly knew this, and had become accustomed to carefully selecting the right candidates, buffering requests for young people's voices (from journalists, researchers, funders, referrers), and mediating between capacity and ideal with supportive interventions (in the filling in of forms, for service evaluations, for ideal therapeutic modalities). Sam and Gulliver's cases illustrate the idea that a young person who can, or will, express their experiences and needs in words upon request, and find that experience empowering, is idealistic and exclusionary (Kirmayer 2000). There are a range of medical, behavioural, emotional and political factors that could impact on the way young people speak (clarity of sounds, tone, volume, their experience of speaking, their willingness to speak to me, or to record their voice, or the possibility of intended audience understanding them). For example, anxiety has an impact on both the sonal qualities of the voice (Lundh et al. 2002) and the speakers' evaluative judgements of the sound of their own speech (Özseven et al. 2018).

Furthermore, those who had undergone traumatic experiences may have found it particularly challenging to articulate their experiences in comprehensible form. Ethnographers have identified the pressures that can be placed on victims of trauma to 'open up' and tell their story, or to tell it in particular ways both in therapy and in research, which contrasts with observations that trauma is often handled among close friends and kin through shared silences (Kidron 2009; Warin and Dennis 2008). Philosophers Larrabee, Weine and Woollcott pose the question, 'where the meaning of one's life is disrupted, what words can be found?' (2003, 354); and, as feminist folklore scholar Diane Goldstein argues (2012), a demand

to find such words may be neither therapeutic not empowering. Alison Cook-Sather sums up resonant problems as 'the impositional potential of liberatory efforts' (2007, 390).

One way of addressing these challenges is to insist on flexibility in the apparatus used for listening, such that more variety of forms of expression can be accommodated. Some researchers or practitioners have used creative methodologies for engaging even 'hard to reach' voices, including, for example, inviting photographs (Bloustein 2003), arts (Juffer 2016, Nugent, Glowa and Shaw 2022), digital storytelling (Anderson and Cook 2015, Lambert 2013), or the use of 'yes/no' or pictoral cards (Komulainen 2007) for those who can't, won't, or shouldn't be asked to express their preferences or experiences in words. This means more forms of knowledge and communication can be included, which is academically enriching as well as politically more inclusive. However, this is a complex solution, in that the more work that goes into 'giving voice' to nonspeaking people or unspeakable things, the more requirement there is for the researcher or service provider to support (or convince? Coerce?) participation, and/or to mediate, translate, and interpret non-verbal phenomena into (whatever is to count as) a 'voice' (Wolf-Meyer 2020).

With this predicament in mind, voicework seems to readily invoke its own critiques: rarely is it completed naively, without caveat, cynicism, irony, or anguish. Over the last three decades, many scholars have debated the problem in which the *idea* of 'giving voice' holds currency, while the *practices* of 'giving voice' fall short (Atkinson 1997; Carel and Györffy 2014; James 2007). Critique often centres on two key themes. These are authenticity (are subordinate voices *really* heard?) and empowerment (how much agency did subordinates have over the way their voices were collected, edited, and used?). Recently, with authenticity and empowerment in mind, several authors have found the term 'ventriloquism' useful to highlight the eerie perversion of an author speaking while pretending the words have come from a silent, puppeteered party (Carter 2002, Sexton and Sen 2018, Silverio, Wilkinson and Wilkinson 2022). For different reasons, and in different ways, Sam and Gulliver are particularly at risk of ventriloquism if they are going to have something like a 'voice' represented within research, yet they are also particularly at risk of exclusion if we are not to permit somebody else to pen their perspectives.

To accommodate communicative variety amid a context that cares about authenticity and empowerment, 'voice' can become more of a metaphor than a descriptor, and as a metaphor, it can come to stand for *intentional expression* (hence, authentic and empowered). For example, Sirkka Komulainen (2007), describes how workers in a specialist nursery in the UK tried to empower the nonverbal children they cared for. The carers she observed tried to engage with what they called the children's 'voices' by looking for behaviours that might count as those children's expressions of choice (for example, gesturing to one of two food items presented). In her portrayal of the ambiguities that ensue (did the child really point to something, or was it an error? What about gesturing to food and then appearing unenthusiastic about eating it?), Komulainen shows that the notion of voices as intentional expressions oversimplified and obscured the messy political realities of delivering care amid unclear remits and requests.

Komulainen's case study is an example of the way voicework (even with metaphorical 'voices') often involves what linguistic anthropologist Alessandro Duranti calls 'hyperintentionality' (2015). Ideal communication, in hyperintentional moral contexts, is all about intentional expression and the expression of intentions. One concerning aspect of hyperintentionality in care provision is that people may be treated as full and deserving persons only in as much as they can be understood as authentic communicators and intentional choosers (even as more people may be understood as authentic communications and intentional choosers via flexible and creative methods). The risk is the exclusion or belittlement or denial of those needs that *can't* be clearly communicated as intentional choices/voices (Wolf-Meyer 2020). This concern complements Annemarie Mol's highly influential arguments (2008), that people should not only be cared for in as much as they can choose their care. Following Komulainen, Wolf-Meyer, and Mol in this case, means rather than finding ways to include Gulliver and Sam as persons who are competent in expressing their inner state after all (if only we can listen in the right way, with flexible modes and mediations, being cautious of ventriloguism); we could instead use their cases to think more radically about what is required of care given that personhood *does not* equate with a vision of 'healthy agency' that relies on competent, intentional communication in organising the meeting of one's needs.

This line of argument follows the achievements of poststructuralist and feminist analysis which has established that it is not only those without a material voice who may struggle to articulate their needs or experiences (Goldstein 2012). For example, Patti Lather writes against the 'romance of the speaking subject' in ethnography (2008, 20), and in her own book about women who have HIV (Lather and Smithies 1997) she aims to render her subjects incoherent and fragmented, in order to push her readers' to acknowledge that they *cannot* fully grasp an authentic experience of these women, or the disease. Similar critical moves have been made by those commenting on the 'multivocal, messy, non-normative' aspects of children's voices, (Spyrou 2011, 151; also Mazzei and Jackson 2009). In this way, the distinction between those who have and do not have an audible voice is blurred in the opposite direction: not by suggesting that those who don't speak are intentional, comprehensible communicators after all (as attempted in the nursery Komulainen observed), but by emphasising that even those who do speak

cannot be expected to equate their needs with what they can say about them in any particular context.

Yet even methodologies like Lather's focus on the moral aim of apprehending people's needs 'on their own terms' (which might well be, fragmented and incoherent). 'We try to not position ourselves as knowing more about these women than they know about themselves' says Lather (2008, 23) sounding remarkably like those who work in the pursuit of 'authentic' (Lather may say 'romanticised') portrayals of voice: both involve a deferral of authority which is at the same time, a demand of expression. Similarly, when childhood studies scholar Spyros Spyrou argues for more reflective awareness of how voices are shaped and produced by research methods, he does so in a bid for 'new, more productive ways of producing and representing children's voices' (2011, 152). Lather's interest in incoherence; Spryou's in situated notions of voice; Silverio's concerns about ventriloquism; and Komulainen's nursery workers' eagerness to find children's 'voices'; all have in common concerns with the principle question of voicework: have they been heard? Have they been properly regarded?

For all of the good work and critical thought that happens in pursuit of the question 'were they heard?', one risk is that that line of enquiry defers attention from a subtly, but profoundly, different question: 'What response did they garner?' The next section will clarify why a distinction between these questions is important.

## The exhaustion of voice

As I moved forward in planning the podcast, it became clear that recording young people was not granting some unanimous pre-existing wish to be heard, but bringing an extra burden that not all young people would want or be able to bare. Far from 'giving voice', *getting* voices was not an easy harvest. So, staff recommended young people—Hermione and Luna—who had been attending for quite some time and had established relationships with the centre. They were articulate, confident, and staff felt they were likely to enjoy the project and benefit from it.

I already knew the girls well from fieldwork. Hermione was quick-witted and chatty, tall, with her curly hair pulled into a pony-tail and thick glasses; she had a frequent contagious laugh that was sometimes tinged with anxiety. Luna was more serious and reserved, often hiding her eyes behind a pulled-down baseball cap. Both were warm, brave and sincerely committed to the horses.

We began the podcast with a collaborative planning session, to which I'd brought a large piece of paper and pens, in the hope we could brainstorm things to include. For some time, there was a strange, uncomfortable sort of choreography where I tried to withhold any guidance so that they could steer the plans about content and form, while simultaneously they tried to guess what it was that they were supposed to do, reading my responses for verification. Eventually, I prompted: 'If there is anything you want people to know, to help them make decisions about how to help young people, this could be a place to say it.' This seemed to ignite them with a sense of purpose. They said that they wanted to talk about the need for easily accessible, flexible funding, so that young people could get the care that they needed. 'It's not strictly about the horses,' Hermione said, 'but you can't get to the horses without funding, so would that be alright?'

The transcript below is taken from the subsequent session in which we set out to make a recording about funding. It is much longer than readers are likely to be used to reading in published articles, rather than in raw datasets. I ask for your time, and care, in sitting with this data. One of these voices can no longer be heard and deserves regard. There is no better place to stretch the expectations for style than in an article dedicated to discussing the relationship between voice and care. My aim is that you are moved by the discussion, as the discussants were, rather than to condense or extract the key learning points. With this in mind, please attend to pace and form as well as content as you read.

Rosie: Do you guys know how you were funded before?

Hermione and Luna, in sync: The hospital paid for it.

L: And also, our school.

H: So, our—originally our hospital when we were in hospital together, then in school, school paid for it.

R: So now, did you get to the end of what the school would pay for?

H and L: We finished school.

R: So, you wouldn't have an option to continue with it?

L (quietly, to H): Do you mind me saying how you get your funding?

H: No no, go for it.

L: You're on an EHCP—so educational health care plan.

R: Do you mind explaining that in case people don't understand?

H: EHCP is kind of where—do you want me to hold that [the dictaphone, *laughter*]—an EHCP—an education and health care plan is where your health care team and your education team—educational team?! I mean your school—

they come together and create a plan—health care *plan*—see—to make your school life easier—well your life in general easier—hopef[ully]-—that is the aim. And—

L: Yeah.

H: So, the person who did my whole application for my EHCP had it in the requirement or in the conditions that my local council would pay for me to come here if we did need that money so I am—the local authority is paying for me to be here.

L: Which is quite interesting because I applied for the same thing and—

H: And it is exactly the same. So, what Luna applied for is the exact SAME THING that I asked for—

L: And it is pretty similar situations. But it depends what council you are in. Obviously I'm not going to say what area I'm in but we are in separate areas and that really does play a part and certain councils are more lenient than others cos obviously funds and stuff. So that's quite interesting about different councils and stuff isn't it?

R: So, you have to pay it differently now?

L: Yeah, I've got to pay it by myself.<sup>4</sup>

R: So, if you'd have, it could be, I don't know I haven't been through the process of applying for this sort of thing, but could it be that the people who make the decisions about what to tick yes to in an EHCP don't understand the value of programs like this?

H: Well no—fuck! Luna wasn't even granted an EHCP, let alone the funds to get here.

L: For me it would have been the mental health side which should be just as valid as a physical side.

R: So why weren't you granted one do you think?

H: Well my school made the application, my old schoo—we were going to different schools at the time—my school made the application so I—we—applied, we got it, it was all—the things that I got—what are they called? the *provisions* I got—extra time for exams, breaks in exams, teacher support,

<sup>&</sup>lt;sup>4</sup> Through an earlier conversation, I know that Luna budgets her therapy out of her Disability Allowance.

coming here, a room at school, that was all in on the EHCP so when I got to college—

L: You had a lot—

H: I had a lot of stuff already in place so I didn't have to do any assessments or more applications to get those provisions. But *Luna*—[laugh of disbelief]

L: I was just thrown into it-no-one knew-

H: it was the same needs but—

L: No-one knew—I can talk about this right, they are not going to know it's me, right?

R: Yes, you can talk about it if you want to, then we can—[I was going to say, 'edit it out later if you're concerned', but Luna interrupts me]

L: 'Cos I have psychosis, and I have, um—when it comes to loud noise, and I tried to—if there's an alarm and I try—I will—well—[H laughs knowingly, supportively, L laughs too] Well, when we were at our old school and there was [an event] one day [the series of events that follow are removed from transcript to preserve anonymity] . . . that's the severity of it. I'm—it's—I am not in control of my actions and my anxiety like—and other things with my mental health in general and um none of the college knew about it and I tried, I tried to tell them but they weren't listening it kinda—

- H: If she'd had an EHCP-
- L: They were like, 'No you can't have an EHCP'—
- H: If she'd had an EHCP she would have had—
- L: 'Cos you had a learning support person with you all the time and-
- H: I did. I didn't appreciate it. I didn't want it! But I had one. And I did need it.
- R: Did they tell you why you couldn't get one?
- L: I can't remember.
- H: They just denied the application. [She throws her hands in the air.]
- L: They don't have to explain it.
- H: They don't have to at all.

R I was thinking one of the things you wanted to convey on here is how valuable places like this are so that they can get funding to help more young people but it sounds like the problem with funding is more systemic than that because it isn't about the stables per se, it is about the recognition of your needs in the first pl—

H: Well actually also they didn't want to give me the funding for this, the person who—what are they called—my—?

L: Advocate.

H: My advocate—there's like a person at—in the council who you are assigned to and they basically plead your case, they are like, 'right, this is what she needs give it to her now!' [She thumps her fist in her hand.] And this woman fought so hard to get the funding for me to come here so she had—it took months—and there were arguments—and they pulled up all my old records from the hospital cos somewhere in there somebody had said once—what's my name—'Hermione'—really benefits from coming to the stables and it said that and that is the basis on which I got the funding to come here. It is impossible! [She laughs incredulously.]

L: You almost need evidence, and they don't trust you when you say you are struggling—

R: Huh?

- L: Like it isn't enough—
- H: You have to be—

L: This is the part I really disagree with, to get help you have to—

H: You have to prove you are unwell.

L: Yeah, you have to get to a really really bad stage in order to get help you can't get help 'til you get to that stage so you basically have to be like—um— not really in control—you have to be like—you can't look after yourself and that's when you get help and *that's* when you get help [sic], rather than, like, six months before you say I'm feeling this way, I'm in control of it now, but if I don't get the help I'm not going to be in control of it and they say 'we'll'—

H: 'We'll help you when it comes.'

L: 'We'll help you when you're fucked,' basically.

H: 'We'll help you when you're about to die.'

H: 'And then and then—'

L: And then you're not in the capability to do the horses so-

H: You can't leave the hospital, you can't go to school or-

L: I didn't leave the hospital for 16 months. It was ridiculous. I didn't do anything, I would literally just stayed [sic] inside the entire time.

H: It's not like you couldn't go into the garden, it is that people didn't make the time to take you into the garden.

L: We'd say, 'Please can we go outside for five minutes?'

H: Or even to come to the horses. Sometimes they just wouldn't. They'd be like, 'nah, can't this week.' Or, 'We don't have enough members of staff to come here.'

L: Oh my god! Even!

H: Urgh! They were so understaffed—

L: At one point I got leave like—it's called 'grounds leave', where you are allowed to leave the hospital and walk around the grounds—um, and I got it certified but then there wouldn't be enough—well, there was if they actually tried, because they let other kids who had home leave, and I didn't even have home leave, and they wouldn't let me, they'd be like, there's not enough staff, we can't take you outside, and it would be like a week and I'd have had it for a week and I'd be like, you're not motivating me at all, what's the point in getting leave, you're not—it's—it's—[Luna shakes her head, finding the words]—it's—

H: At that point, she hadn't left the hospital for months. She had not left the building. She hadn't gone into the garden. She hadn't gone outside. They didn't let her out.

[They pause, and look at me for a response, incredulous and fired up about what has happened. I pause too, stuck for words, and try to formulate an appropriate way to reply.]

R: Can I just say, you should be so flipping proud of where you are at now. I didn't know you guys' whole stories, I just met you as people who are pretty darn good at horse training and nice to talk to and I am shocked and so sad to hear what you've lived through.

H: She could not come out. She was kept inside. So she could have gone in the garden, the garden was secure, we were allowed to go out whenever we

wanted even if we didn't have leave we should have been—but they would not let us go out because they didn't have the staff—they said they didn't have the staff but they didn't have the time—there was other things going on—

L: You could see them in their office sat there doing fuck all. And it's a pattern as well, it is not just one hospital. Because I was at two hospitals. Obviously in hospital you meet a lot of people and they have all said very similar experiences. I genuinely, like—I can't, like—I can't—[Luna pauses. We are sat on hay bales and she has begun ripping strands of hay into pieces. Her hands are shaking, and she bites her lip. She looks like she might be about to cry.] For me, this is basically the limit for how much I can talk about it because it has affected me so much. And the worse part is that half of the stuff that really affected me could have been stopped if the staff did their jobs properly.

R: I don't want you to feel like you need to talk about your own cases in particular, if it's hard to talk about, but the route we have kind of gone in has taken us there but—

L: I think it is important because no one talks about it, and I want to be able to—I think maybe in a couple of years' time I will try to actually reach out to my experience in hospital because I think people would be shocked if they knew half the stuff that actually happened. It was 100% like—[she pauses, and audibly breathes in and out]—abuse. 100%. Especially at my other hospital and for the other patients as well, like, it was terrible, like—[she pauses and audibly exhales again, looking exhausted.]

H: I was there when Luna was at hospital, I was there and she hated it—quite reasonably—and I went to visit her in her second hospital and she was like, 'I wanna go back.' The second one was that bad. She was like, 'I wanna go back to that place where they didn't let me out, that I hated, because it is so, so, so bad here.'

#### Disarticulation

Our conversation had started out at funding challenges and EHCP bureaucracies and quite quickly ended up at inpatient neglect and abuse. The common thread was the experience of being dismissed, cries for help being ignored, being pushed away and piped down. We *could* say this transcript evidences a need for greater patient voice within their care. Luna was clearly denied authentic empowerment in relation to her care. Yet, note the form of the conversation as well as the content: Luna and Hermione support one another's stories, rather than telling them independently. The conversation moves through topics, building pace and force, and ends up on themes that none of us were completely sure we wanted or were in control of. These points support arguments established in the previous section, that speech is neither as essentially individual, nor intentional, nor therapeutic, as the idiom of voice-as-agency may suggest (Lather 2008; Goldstein 2012). The transcript seems to both support the need for Luna to be given more voice, and yet also the futility of expecting Luna's voice to overcome the challenges before her. I was struck and saddened during that conversation, and when listening back to it, because I wished Luna and Hermione had not had to take up a position of advocacy, and constantly try to articulate their needs in order to get them met.

While the notion of 'giving voice' seems to draw on the idea of a morally positive public forum for debate and communal decision making, Hermione and Luna talked about having to fight. Voicing their needs did not seem so much like exercising a right as withstanding a demand, an endurance, and grappling with an impossible, unfair and precarious task. Finding voicework was required of them; Luna and Hermione had sought out care in a world of allies and enemies, strategies and luck, with tooth, claw and nail. Sometimes someone said just the right thing, to just the right people, in just the right way, in order to get help. At other times, they seemed to be shouting into the wind. Therefore, rather than read Luna and Hermione as asking for better representation, I read them much more directly as incredulous that they were not given better *care*, and weary of the need to represent.

Luna and Hermione's dialogue demonstrates how care, in some contexts, has become dependent on advocacy and articulation. Voicework is required to make things happen in relation to unmet needs, limited resources, unwieldy infrastructures, and unaccommodating mediums of expression: the onus is on individuals, even children, to make effective claims.

Luna and Hermione are not outliers in terms of their experiences of struggling for care. In 2015, only 25% of those young people with a probable mental health condition accessed treatment for it (Department of Health 2015), and in 2023, the Children's Commissioner reported that 40,000 children waited more than two years for support or were still waiting at the time of the report (Children's Commissioner 2024, 7). Newman et al. (2024) describe the process of accessing youth mental health support as akin to a game of 'snakes and ladders' while one parent summed up the process as 'the most soul destroying, frustrating path I have ever been down.' (Greally 2023, 19; also Crouch et al. 2019).

For feminist linguist Deborah Cameron, it is never an innocent or neutral event when something becomes understood to be a 'problem with communication' (2000). She notes that it is the dominant party who is usually able to define a conflict or relationship problem as a 'miscommunication', as though problems would be overcome if only the parties *understood one another*. I don't believe a sinister political intent is at play in the persistent labelling of young people's unmet needs as unheard voices—but I do note that such a definition places demands on young people to articulate their own needs and allows a lack of care provision to be interpreted as ultimately stemming from a lack of understanding. 'Nobody knew', said Luna about her mental health needs at college, but that not-knowing, not-listening, not-hearing, was most significantly a not-providing, a neglect of care, a lack of response. It *could* be framed that had the school or hospital properly known about her problems, then they would have responded differently. What would be needed, then, is ways to help Luna shout louder. But I'm suggesting there is mileage in flipping the primacy of focus—had school/hospital workers been systemically and therefore interpersonally able to respond, then *they would have* known, and cared, better.

What we need, then, is a terminology that draws attention not only to 'voice' (which, however flexibly conceived, inevitably places onus on the speaker) but to the scene of address in which an audience is, or isn't, moved to respond.

The term 'articulation' is useful here for thinking about personhood and communication thanks to its dual meaning (it has been helpful to others too, most prominently following Stuart Hall). On the one hand, it refers to the process of putting something into words. The advantage of articulation over 'voice' is that we are not drawn to think of something that comes from within, as authentic and unique to an individual as a fingerprint or soul. We are drawn instead to apprehend the challenge of making something communicable with the shared medium of available vocabulary. In fact, I'd suggest leniency in applying the concept of articulation in thinking about how people can articulate even without words. When Gulliver stared me down and turned away, he articulated in available mediums that I shouldn't come closer. Hermione's local authority 'advocate' articulated her needs for equine therapy on her behalf, no doubt through a range of infrastructural media including forms, budget sheets and meetings. In a bid for care, one must articulate within the parameters of available discourses, services and resources. Luna's advocate didn't articulate her needs so successfully, or Luna didn't even get so far through the application as to get an advocate articulating on her behalf.

The second of the dual meanings of 'articulate' is a flexible join, or link, like an articulated lorry, or in anatomy, an articulated joint. Articulation, says Hall, 'is a linkage which is not necessary, determined, absolute and essential for all time. You have to ask, under what circumstances can a connection be forged or made?' (in Grossberg 1986, 53). At least at some points, Hermione's needs had been articulated through a system—linked to a system—that could (at least somewhat) be moved to respond. Tragically, both girls demonstrated that in order to be articulate within this system, they needed to fall into greater depths of suffering

and risk ("we'll help you when you're fucked", basically'). They then fall into a double-bind (Bateson et al. 1956)—overridden because they aren't ill enough, or overridden because they are too ill to have control over their lives (and for a similar communicative politics in a different care context, see López 2020).

To 'disarticulate' is a butcher's term, it means to chop something off at a joint. In her EHCP application, at college, and in hospital Luna had been disarticulated, cut away, her call for help was rendered inarticulate; it did not connect with moving parts. Her problem was not a lack of voice, but the systematic disarticulation of her needs—she was shouting into the wind.

#### **Response-able research, articulating for others**

The idea of dis/articulation suggests a remit to study the curtailment of responses to young people's needs, as a critique of the futility of voicework in care provision, and as a (sometimes, critical) complement to research that platforms and produces young people's voices. But can we also adopt the ideas of response-ability and dis/articulation into our own research ethics and methods?

The week after that first podcast recording, Hermione had told me (off-dictaphone) that her own funding was now in jeopardy. She had recently turned 18, and once the school year was officially over, her EHCP plan would end. She hadn't been granted disability allowance, as Luna had, and so she would have no way to pay for her equine therapy in the future. She told me this as an example of the sorts of problems young people have with funding-turning 18 being one of them. She spoke of those issues in a register of speech typical of voicework, on the one hand, as a spokesperson for 'young people' to a potential intermediary to power, and on the other, airing frustrations in a way that was hopefully somewhat therapeutic. Within that register of speech-voicework-my ethical role was to provide a supportive space in which she could feel heard. To do justice to her (somehow, not obliterated) faith in voicework, my ethical duty was also to subsequently platform that voice in relevant publications or venues, at best, impacting on future decisions about post-18 funding (for example) so that things might work out better for some other kids like her, in some other time. Therefore, I listened with care, diligently recorded her comments about funding problems (among other things) and I pondered what best to do with that data. This is what ethical voicework meant to me. at that time.

When I received the phone call some weeks later to tell me the devastating news that Hermione had died, I was hit with the futile question—what could I have done? To even ask the question, let alone to answer it, I know is to simplify the problem and reduce the depth and complexity of Hermione's life and death, both of which existed well beyond my knowledge or reach. I know that suicide is not an event

that allows any simple story of causation. I don't claim any sort of substantial or comprehensive knowledge of Hermione's life, or any significant influence upon it. But, following the loss of Hermione, the genre of ethics I had adopted through voicework—an ethics of co-production, listening and platforming—seemed so sterile, withholding and cold.

It hadn't occurred to Hermione, Luna or I that our conversation could have taken on a different register: that of call for help and response. This would have meant not giving/getting/platforming their voices, but responding to their predicaments as though I was inculcated by hearing about them. For Donna Haraway, responseability means both the capacity, and therefore, the imperative, to respond to others, by remembering that 'we are face to face, in the company of significant others'. Such response-ability is challenging, and imperfectible, because it cannot wait for clarity of the remit in order to act (2008, 88–93)

I couldn't fund Luna and Hermione directly, but I could have taken up the challenge of articulating their needs—making things move on their behalf. Who else could have funded them? What other systems or services could have been triggered? What schemes initiated? Could I have acted as a 'go-between' (Hoechner 2018) on their behalf? Even if I could make nothing move through my efforts, what sorts of things might I have learned about inarticulacy and disarticulation along the way? What would it mean, academically and ethically, had I approached our encounter with a focus not on making space for Hermione's voice, but on helping her to garner an appropriate response?

My paper isn't claiming that its novel contribution is the idea of getting involved in our field site to make things better (Biehl and Adams 2023; Singer 1995; Whitley 2014). Instead, the contribution is turning attention to the systematic and interpersonal factors that enable or stunt articulate responses to declarations of need—in our own research as well as out there in the world. In fact, this resonates with longstanding critical moves to reconfigure attention toward the scene of address in which those with mental distress or apparent anomalies are able to speak, rather than only on the words that they say (e.g., Laing and Esterson [1964] 2016; Bateson et al. 1956; Kirmayer 2000; Goffman [1961] 2017). It also resonates with other ethnographers of childhood who have noted the ethical complexity of navigating relationships with children in research settings raising issues, for example, of how safeguarding disclosures should be handled (Holt 2004), what to do about dangerous, or criminal behaviour (Feixa 2023), or how to think about the risks of raising aspirations for changes that may be hard to meet (Hoechner 2018). Yet I want to add to this discussion that it is ethnographically noteworthy, and ethically important, that neither Luna and Hermione, nor any of my research ethics committees, reviewers, peer commentators, nor field site gatekeepers, nor I, ever

asked how I was going to substantively *respond* to needs I encountered in the field (ethical concerns were focused on how I would *represent* subordinate voices).

Some anthropologists may sensibly contend that it is not our place to fix things in the field, and it is true that anthropologists are not and should not pretend to be therapists, funders, referrers, or professional politicians. But we must also recognise that a jurisdiction logic is part of the problem to be studied and, when appropriate, countered: The gathering of voices-in research, and in service infrastructures (e.g., in diagnosis, in treatment decisions, in funding bids, in service evaluations)—is often dislocated from the organisation of a response (which must be approved, prescribed, arranged, funded, accommodated from elsewhere). Voices shout up the ladder, and, belatedly, resources (sometimes) trickle down. This means that practically, once voicework takes precedence, response is displaced to some other time, or even, for some other people, or at some other scale. The pervasive genre of voicework—even done with care, and despite real and valuable achievements-does not always register descriptions of need as generating an immediate ethical incumbrance on the listener to respond to that need with anything more than a kindly ear, an appropriate recording process, or a signpost. The 'voices' thus harvested are not voices like those described in Plato's Phaedrus—souls in touch through the immediate phenomenon of responsive dialogue. That dictaphone reminds me that I was carefully collecting voices under an ethics of representation over and above an ethics of response.

#### **Moving forward**

The aim of this article is not to give up on voicework. To do so would mean giving up ground that has been hard-won and that is still under siege. Childhood studies and disability scholars argue that we must not preference the voices of adults, or of 'healthy' people, in the presumption that others are incompetent, passive, or unable to make meaningful decisions about their lives. Allison James (2007), for example, derides children's policies that portray children in terms of need, as victims, or passive objects that adults must reside over, and Guro Parr Klyve (2019) repeats that assertion specifically in relation to contemporary children's mental health research. I agree with James, Klyve and others that children must be recognised as important, complex persons whose experiences must matter more in the delivery of their care. But, at the same time, voicework concerns can play into a common dichotomy which holds neediness associated with passivity and even objectivity on the one hand, and personhood, along with competence, intentional expression and the capacity for choice, on the other. Arguing that children or care-recipients are persons in as much as they have agentive voices after all, seems to risk supporting an unfair demand: 'Look, she's not an object, because/so she can articulate her own needs.'

More helpful, I think, are feminist theories of care (e.g., Mol 2008, Sevenhuijsen 1998), in which a recognition of neediness and incoherence is not a denial of personhood. To treat one as a person does not mean to recognise that they can produce competent choices and intentional expressions, but rather, being a person means being responsive, dependent and incumbent. Personhood is more, and less, than self-advocacy. With this notion of personhood in hand, voice is less idealised as a solution to the politics and ethics of care, but representational problems are not disbanded. Problems endure in making sure that care responds to diverse experiences, values, and priorities, rather than projecting recipients' requirements onto them. These problems are exasperated when care-recipients are less able to articulate their needs effectively (for medical, personal, political or other systemic reasons). So, care must always involve critical reflections regarding projection, presumption, and the politics of knowledge (although response-ability cannot wait for those issues to be resolved). I'm not advocating, then, for disbanding the value of voicework, but for a pivot in focus, a shift that brings the listener-responder under scrutiny rather than the speaker. This draws attention not to the voicelessness of the ventriloguists' dummy, but to failing machinery of the limp, late response, or to the tragic predicament of those who yearn to be able to offer a solution to the young person before them, but, for very many reasons, can't, don't, won't, or at least, as in my case, didn't.

After our recording, Hermione and Luna's usual session leader, Grace, recommended some time with the horses in order to re-regulate emotions before heading home. The girls asked if we could give Spirit a bath. Spirit was a hairy, rotund little pony who got itchy and sweaty in the summer because of a metabolic disorder. She was fairly new to the stables, and hadn't yet learned that a wash off could be pleasurable. In the sunshine, the girls set about getting Spirit comfortable, tenderly, tactfully. They read her reactions to figure out which bits felt good, when to go slower, when to distract her with an itch on her neck or the nibble of a carrot. Once she was gleaming and clean, she stood quietly munching hay in the sunshine, drying off. Luna rested on an upturned bucket against a stable wall, with her face tipped toward the sky and her eyes closed, perhaps sucking in the sun's rays, perhaps listening to the hay-munching, while Hermione guietly ran her fingers through Spirit's mane. The minutes passed gently. Hermione had told me, on another occasion, that she loved the peacefulness and quiet of the horses. Like several of the other young people, Hermione had also said that it felt rewarding to get along with the horses, because of the way they responded to your body language. That meant, if you were cross, or sad, or frightened, the horses reacted to it—not always well, but always instantly. They always noticed. Horses didn't say one thing, and do another. And, Hermione has told me with a half-smile that told of exasperation, horses didn't make you talk about your feelings. In hindsight, that half-smile seems like a recognition of tragic irony. I was yet another adult who wanted to hear her express herself, and who could offer nothing more than a platform, or a signpost, or sincere regard.

Too often in British young people's mental health care, nobody can, or nobody does, respond in such a way that young people feel authentically noticed and cared for, despite the barrage of messages that 'it's good to talk' and that 'patient voices matter'. Those statements give the false hope that care is initiated by 'voices' (meaning intentional expressions) such that once one has been properly heard, then one will be cared for, or even that *in* being properly heard, then one has already been cared for. It does something, when we converge the questions 'was she heard?' and 'was she cared for?', it draws attention to the absence of voice, more than the absence of response. Too often, while young people's voices are, at least ostensibly, hyper-valued, their needs are disarticulated. This article is not a solution to that, it is not even a comprehensive description of the scope and shape of that problem. It is a resolution to better articulate the needs of those who are suffering, who shouldn't have to give voice to get care. That means not merely listening, but making things move.

## Authorship statement

I am the sole author of this work.

# Ethics statement

This research received ethical clearance from the Research Ethics Committee at the Department of Social Anthropology at the University of Cambridge in October 2020. Written consent was obtained from all participants discussed in this article. Pseudonyms are used throughout for people, places and animals, and some other details have been fictionalised to prevent identification. Both the research methods, and a draft of this article, were assessed for unintended harms by the safeguarding leads and directors of each of the Equine Assisted Therapy or Learning Programme that participated in the research.

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