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## research article

# Kindness and curious kinships in the lives of family carers of adults with learning disabilities

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This article engages with transcripts from 12 family carers to explore kindness in the lives of family carers and adults with learning disabilities. Knowing that kindness matters and understanding it to be linked to an expansive notion of kinship that transcends familial ties, we examine its presence and absence in interactions between family carers and health and social care professionals, services and systems. Our findings show how a lack of curiosity and disconnection from kin hinders kindness and isolates carers, highlighting the need to embed a socially just, cultural politics of kindness in health and social care services and systems.

**Keywords** care • family carer • learning disability • kindness

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## Introduction

I think it's just literally about being kind to each other. We are all human beings. Just be kind. (Natasha)

This article explores kindness in the lives of family carers and people with learning disabilities. We were drawn to discussions of kindness as part of a wider research project carried out in England: 'Tired of Spinning Plates: An Exploration of the Mental Health Experiences of Adults and/or Older Carers of Adults with Learning Disabilities' (National Institute for Health and Care Research [NIHR] 135080).

The project aimed to explore how family carers of adults with learning disabilities (henceforth referred to as ‘carers’) conceptualise and experience mental health, services and support. We centre the experiences of carers and adults with learning disabilities, which are often marginalised within research, policy and practice (Smith et al, forthcoming). The project was developed and co-produced with carers and people with learning disabilities. We engaged principles of co-production because we believe that experience matters and co-production has the potential to open up different ways of understanding experience (Runswick-Cole et al, 2024a; Hamington, 2018). Carers tell us that kindness matters: ‘just be kind’. Yet, in Global North sociological scholarship, there is a general agreement that kindness remains under-theorised (Habibis et al, 2016; Atkinson, 2019), and despite the broader cultural presence of kindness, it has historically lacked the ‘heft’ of solidarity, justice or community (Brownlie and Anderson, 2017: 1223). By thinking with and through the lives of carers and people with learning disabilities, we pay attention to what kindness is and to what kindness does in the worlds people inhabit (Willis and Kavka, 2021). In doing so, this article contributes to the growing literature that pays attention to the cultural politics of kindness. We emphasise the need for embedding a socially just, cultural politics of *kindness* in health and social care services and systems that are entangled with the lives of carers and adults with learning disabilities, not least because people with learning disabilities are among the most marginalised group in the UK and wider world (Goodey, 2015; Simplican, 2015).

### *A note on terminology and an invitation to kindness*

During the project, carers and people with learning disabilities consistently questioned the terminology that shapes our inquiry: the categories of ‘learning disability’, ‘carer’ and ‘mental health’. They asked that we value diversity, resist attempts to other them and the people they care for, and celebrate the disruptive potential of difference (Cluley, 2018; Runswick-Cole et al, 2024a; 2024b; Smith et al, forthcoming). Throughout this article, we remain sensitive to the repercussions of the words used and ask readers to do the same (Epstein, 2013; Smith et al, forthcoming) while acknowledging we all have entanglements with these systems and services.

## **Care and kindness**

We approach theories of care and kindness, drawing on a feminist politics (Magnet et al, 2014) and on critical disability studies scholarship (Goodley et al, 2018), both of which emphasise the political significance of emotion and embodied knowledge. We do not conceptualise kindness as ‘a pure feminine emotion’ (Magnet et al, 2014: 2); rather, we understand care and kindness as affective and deeply political, as well as, therefore, always being potential sites of ‘(in)justice’ (Nishida, 2022: 43). We are sensitive to the ways in which care is conceptualised through assumptions about gender, race, class and (dis)ability (Magnet et al, 2014: 4). People with learning disabilities are routinely positioned as passive recipients of care rather than as carers themselves (Ward, 2011). It is often women who undertake caregiving roles, with women from the Global South filling care gaps in wealthier countries (Hochschild, 2000). Therefore, our attachment to kindness in contexts of care is not sentimental but,

rather, decidedly ‘unromantic’ (Magnet et al, 2014: 6). Kindness is neither an ‘innate ability’ nor something that must be ‘felt’; it is a social justice issue. Furthermore, as we argue later, there is also ‘a duty’ to be kind in communities, including in health and social care services and systems (Jeffrey, 2016: 261).

Our discussion of the political significance of kindness takes place in the context of the health and social care services and systems as they are encountered by people with learning disabilities and their carers in England. These services are under severe pressure following years of economic austerity (Bach-Mortensen et al, 2024). We understand these services and systems as affective spaces in which acts of kindness and unkindness are deeply felt and entangled with politics and social justice (Runswick-Cole et al, 2024c).

## Care

In everyday usage, care is often storied as something kind and benign, yet care is described as a ‘dirty word’ in critical disability studies scholarship (Eales and Peers, 2021: 164). Too often, studies of care are reduced to a concern with the physical and emotional labour carried out in a dyadic relationship between a caregiver and care receiver, and disabled people are depicted as dependent and as a burden (Morris, 1997). The maintenance of this dividing line between ‘caregiver’ and ‘care receiver’ has encouraged some feminist scholarship to focus primarily on the gendered labour of care as a burden, while some disability studies scholarship has focused on the rights of the individual recipient of care. Hughes et al (2005) call for feminist scholarship and disability studies scholarship to make common cause, which requires us to disrupt the seemingly neat categorisations of caregiver and care receiver. We follow Douglas et al (2017: 1) in understanding care as messy, always relational and ‘fundamental to being and becoming human together’.

Critically, we recognise the complexity of discussing care and kindness in the lives of carers and of people with learning disabilities while critical disability scholarship documents acts of cruelty, carried out in the name of ‘kindness’ in spaces of ‘care’ across the globe (Fritsch, 2010). These acts include forced sterilisation, painful rehabilitative therapies, physical and emotional abuse, and institutionalisation (Fritsch, 2010). Cruelty in the name of care continues to haunt the lives of people with learning disabilities, and it is delivered by ‘carers’ in supposed ‘therapeutic settings’ (DH, 2012). Care and kindness can only be understood as deeply political and always a potential site of ‘(in) justice’ (Nishida, 2022: 43).

## Kindness

Kindness has been under-theorised within sociological thinking (Habibis et al, 2016; Atkinson, 2019), with the notable exception of Phillips and Taylor’s (2009) book, *On Kindness*. Habibis et al (2016) suggest that the lack of sociological attention paid to kindness is a consequence of the perceived mundanity of kindness; it is, perhaps, considered too everyday to be worthy of analytical attention. In the Global North, there is also a consensus that individuals and societies are becoming less kind (Habibis et al, 2016). Discourses of self-reliance are considered to have corrupted the idea of

kindness, and the rise of neoliberalism, in turn, is cited as an explanation for why people are now ‘less kind’ (Habibis et al, 2016: 400).

Brownlie and Anderson (2017) argue that considerations of the presence (or absence) of kindness depend on an understanding of the concept of kindness itself. Conceptualising care and kindness is, however, a complex task. While the value of cultivating kindness in communities is easily asserted (Magnet et al, 2014), it is harder to explain what kindness is and what it does. Willis and Kavka (2021: 8) turn to Phillips and Taylor’s (2009) cultural history of kindness and Hamrick, (2002) to explain it in terms of ‘sympathetic identification with the vulnerabilities of others’ and ‘the intervention into the life of another’. It has further been characterised as the recognition of and concern for other people’s projects (Clegg and Rowland, 2010) or actions intended to benefit others (Curry et al, 2018). In their review of these kindness accounts, Willis and Kavka (2021: 8) identify a key problem in the way that kindness is often conceptualised; its reliance upon ‘a perceived sameness or connection’ to others. It is much easier to be kind to those with whom we feel a connection, and a lack of connection can promote disrespect in service systems (Entwistle et al, 2024). We are all precarious in relation to expectations of kindness, but this precarity is not evenly felt (Berlant, 2007). Precarity demands we practise kindness even when it feels uncomfortable or uneasy to do so (Willis and Kavka, 2021). This duty of kindness is especially important in the lives of disabled people and their carers, who have been systematically categorised as ‘other’, and so opportunities for connection are diminished.

## Kindness in service systems

It is broadly accepted that people who use health and care systems and services – the overarching structures and frameworks in place to organise and deliver care and improve health and well-being – want to be treated ‘warmly’ (Faust, 2009). Yet, in these service systems, kindness too often appears as ‘matter out of place’ (Douglas, 1966: 44). Physicians are urged to care but not to let ‘their heart rule their head’ (Buetow, 2013: 928), while social work services operate on reason rather than emotion (Tanner, 2020). A reliance on rules and tightly controlled bureaucratic procedures within social work, alongside an emphasis on ‘professional distance’ and reduced opportunities for contact, hinders the experience of emotion and connection, ensuring people accessing services remain ‘the other’ (Tanner, 2020). Thus, it becomes possible for health and care services to be delivered without so much ‘as one atom of human kindness’ (Johnstone, 2010: 32), with devastating consequences for the recipients of care (Ryan, 2017).

With disabled people disproportionately bearing the brunt of austerity measures (O’Hara, 2015), it is perhaps even more important that kindness is embedded within their interactions with services. Yet, for practitioners, emotional distancing and learning to care less about one’s clients can become a way to cope in increasingly pressurised environments (Grootegeod and Smith, 2018). However, for others, acting with empathy and kindness becomes a form of resistance within the workplace, a way to fight back and promote social justice despite the constraints imposed by austerity and neoliberalism (Hill and Laredo, 2020). Nevertheless, doing kindness can be a risky business when it serves as a mechanism to reinforce charity models of disability in which disabled people are constructed as vulnerable, frail and infantile (Mallett and Runswick-Cole, 2014; Hughes, 2019).

We find ourselves drawn to the etymological roots of kindness that entangle ‘kin’, ‘kindred’ (family) and ‘kind’ (type), suggesting that a relation of kindness among groupings remains a central part of human relating (Rowland, 2009). We think together with these etymological roots and find hope in collective responsibility for caring and kinder worlds residing among these etymological traces as we turn our attention to kindness and kinships in contexts of care.

## **Curious *kindness* and kinships of care**

Time and again, the lives of carers and their adult children are contextualised within other worlds: hidden, invisible. Perpetually, these hidden othered worlds do not invoke or invite the conceptualisation of curiosity that we argue is needed for kinships to flourish. For these othered inhabitants, carers and the people they support, it becomes easier to stay quiet and to reproduce and surrender to this invisibility than to begin to share that which is so often other-worldly to oft-disconnected ‘not-quite-kin’. ‘Not-quite-kin’ in this context can, at times, include caring professionals, health and social care practitioners, communities, families, friends, and other carers. Thinking *kindness* means rethinking kinships.

We embrace Haraway’s (2015: 162) insistence that ‘kin is an assembling sort of word’. Assembling counters the absolute divisions of othering that deny the expansive and worlding ties of kinship. A kinship of assembling engages an ongoing relationality that is such in its momentum that there is never a pause to allow the naturalisation of definitions of otherness (Minh-Ha, 1988). Kinship ties are always weaving ‘at least two gestures: that of affirming “I am like you” while persisting in her difference and that of reminding “I am different”’ (Minh-Ha, 1988: 4). This dual movement works to undo the invisibility so many carers depict through a subversive insistence on carers’ lives mattering as kin, whose lives, through the ties of kinship, we are always deeply implicated in (Macchiavello, 2015).

There is an urgency for justice rooted in the troubling times we work in as we entangle with the lives of carers who have shared their experiences of caring and mental health openly and generously with us (Runswick-Cole et al, 2024a; 2024b). We invoke and invite a repatterning of kinships that pays attention to all the ties of kinship, whether professional-kin, familial-kin, friend-kin or peer-kin, and the accountability and responsibility that comes with caring for kin and our collective responsibility for the shaping of *kinder* worlds (Haraway, 2008). Responsibility of this *kind* invites an ongoing commitment to curiosity for kin: have greater knowledge of kin after the encounter than at the start (Haraway, 2008).

We work with an openness to curiosity and what becoming curious with and for kin can do in the contexts of carers and their mental health as a responsibility to parents repeatedly telling us that they want to be listened to, understood and valued as carers (Runswick-Cole et al, 2024a; 2024b). To become responsible for the lives of carers requires a practice of staying curious, practising curious *kindness* as a making of kinship (Haraway, 2016). We resist assumptions to conceptualise curiosity as entangled with empathy as a mode to resist the temptation to assert the self onto the Other (McEvoy and Plant, 2014). The task is to become responsible for strengthening connections with carers as kin, not to speculatively imagine the self as separate from the Other. This curious *kindness* is speculated beyond existing theorisations of sociable curiosity that invite ‘a strong desire to know or learn something about others in society’ (Philips,

2016: 125); we invoke a curious *kindness* steeped in responsibility for kin in a way that is only knowable as inextricably bound with care in all its multitudes and kinship ties (Haraway, 2008): 'I think of making kin as that nurturing, cultivating, taking on these: you have me, I have you, we have each other. We're accountable to each other, and you can't just walk away from it' (Haraway, 2022).

Herein lies the curious *kindness* of kinships that we seek and that fuels the possibilities for *kinder* worlds invoked when we find it, momentarily, in the lives shared through this article. In those moments where curious *kindness* and kinships become undone and untied or are absent, we insist on an ongoing engagement with what this undoing and/or this absence does and speculatively narrate moments of (im)possibility for *kinder* encounters (Haraway, 2022). Speculative narrations offer a 'counter to cynicism' (Haraway, 2022). We seek narrations of togetherness and connectivity, of *kinder* kinships that are urgently needed in the (in)visible worlds of carers and the people they care for (Haraway, 2022) – worlds that are ours and we are implicated in whether we choose to be *kindly* curious about them or not. It is with this curious *kindness* in mind that we now turn our attention to the experiences of the carers who contributed to our study as we engage with their interview transcripts to explore *kindness* within the lives of family carers of adults with learning disabilities. Throughout the remainder of the article, we italicise the kin in *kind* to assert the need for a more expansive conceptualisation of kinships and our collective accountability for justice in the lives of carers and the people they care for.

## Method

The Tired of Spinning Plates project comprised six phases: (1) the recruitment of a public involvement group comprising five carers, four adults with learning disabilities and three university researchers, which met bimonthly, online or in person, to offer guidance and support for the duration of the project; (2) a rapid scoping review of the literature; (3) co-design workshops with carers ( $n = 6$ ) through which carers rejected the original plan to co-design a survey in favour of a co-designed online exhibition about carer mental health experiences (see Runswick-Cole et al, 2024a); (4) interviews with carers of adults with disabilities ( $n = 24$ ); (5) online digital storytelling workshops to produce short films about moments that matter to carers about their experiences of caring and mental health ( $n = 24$ ); and (6) the development of teaching and learning resources for health and social care professionals to inform services and support for carers of adults with learning disabilities. This article reports on the parent-carer interviews from Phase 4 of the project ( $n = 12$ ). MacLure (2013) talks about data that draw you in and seize your attention as data that 'glow'. She goes on to argue that the 'wonder' that data produce is neither simply 'in' the data nor 'in us' but enters into relation with the researchers as 'an event' (MacLure, 2013: 231). Within the parent-carers' narratives, we found ourselves drawn to the presence and absence of *kindness*.

## Participants

Interview data were generated from 12 parent-carers of adults with learning disabilities between August 2023 and January 2024 (see Table 1). Carers were recruited via project social media accounts on Twitter, Instagram, LinkedIn and Facebook, as well as via



the project’s public involvement group’s and steering group’s networks. Participants resident in the UK who identified as carers of adults with learning disabilities over the age of 18 were included in the study.

*Data generation through interviews*

Carers were offered the choice of taking part in online or in-person interviews. Funds were available for care replacement costs for carers and to cover any costs incurred by in-person attendance. We think it is important to highlight that no carers in this study were able to utilise this funding, as nobody had any alternative options for care replacement. Consequently, all data were generated via online one-to-one interviews using Zoom.

Interviews were audio recorded and professionally transcribed. Transcriptions were anonymised and returned to participants for approval and as an opportunity to make any redactions or edits.

*Ethics*

Ethical approval was obtained from the University of Sheffield, UK, Manchester Metropolitan University, UK, and Queen’s University, Canada. We were acutely aware of the demands on carers’ time; thus, we sought to be as flexible as possible to remove barriers to participation. Carers were sent an information sheet and consent form; we also provided ‘easy-read’ versions of the information, using plain-English text supported by picture symbols. We offered dates and times outside of usual working hours where needed, and we sought permission to use Zoom for interviews rather than the university’s Google platform, as carers told us that this was more accessible. We transferred data from Zoom to the university’s secure drive as soon as possible after the interviews.

**Table 1: Participant information**

Name	Carer
Steven	Parent
Katrin	Parent
Crystal	Parent
Lisa	Parent
Rosie	Parent
Kristina	Parent
Natasha	Parent
Caitriona	Parent
Lindsay	Parent
Janet	Parent
Julie	Parent
Chris	Parent



## In search of *kindness*

Guided by post-qualitative writings (MacLure, 2013; Taguchi and St. Pierre, 2017; St. Pierre, 2018), we did not set out with a method of analysis in mind. Instead, encouraged by the words of Taguchi and St. Pierre (2017: 647) to throw off ‘the shackles of preexisting, methodologies that constrain us’ and knowing that *kindness* matters, we sought to read and think with and through *kindness*. Over a three-month period, the authors individually familiarised themselves with the transcripts, reading and rereading them while simultaneously reading and thinking about *kindness*. Acknowledging the entanglement of researcher and data, we annotated the transcripts to note down aspects that ‘got under our skin’, moments of interest or intrigue that fostered further thought (MacLure, 2013). We then came together in a two-day analysis workshop to discuss what we had found.

Although we began by collectively seeking narrations of togetherness and of *kinder* kinship that we believe are urgently needed in the (in)visible worlds of carers and the people they care for (Haraway, 2022), rather than finding the curious *kindness* of kinships that we sought, we were confronted by an absence of kinship and connection across systems, services, the community and individuals. We were also drawn to the micro details of the interactions between carers and health and social care professionals and what this meant for the participants. Two of the authors then reread the transcripts, pulling out relevant extracts and grouping them according to these areas. Further discussion among the four authors and a regrouping of extracts led to a focus on stories of killing curiosity with *unkindness*, of (un)kind systems and processes, and cursory health and social care. To counter this absence of *kindness*, we end this section by writing experimental fabulations as a means for analytical engagement.

### *Killing curiosity with unkindness*

We start with Janet’s story of an encounter with the orthotist that took place more than a decade ago and yet is retold as if it happened yesterday. She describes the moment when she arrived, with her son, for an appointment with the orthotist. Her son wore Piedro boots to support his leg. Janet was greeted at the door by the orthotist with the words: ‘Oh, so you don’t know how to put these shoes on?’. The orthotist began with an assumption of incompetence: Janet does not know how to fit the boots correctly. In the absence of curious *kindness*, there is no space for Janet to explain what happened. They had, in fact, arrived at the appointment straight from school. At school, her son had been in a swimming lesson and, afterwards, the school’s staff helped him to dress; the school, not Janet, had put his boots back on ‘incorrectly’. We read this story through an absence of connection: the orthotist makes a careless, *unkind* remark because she does not take the time to connect and understand Janet’s or her son’s life (Willis and Kavka, 2021). The orthotist also fails to pay attention to her positionality as an ‘expert’.

Janet goes on to explain that it ‘hurts’ when professionals use their position of power to say: ‘Don’t you know how to do that?... Why did you do this? Why did you do that?’ (Janet). For Janet, the orthotist’s comment is more than a careless remark; it is entwined with other moments of disinterest and disconnection, an abuse of power that permits *unkindness*, and even decades later, these moments continue to be felt

in carers' lives. In Janet's story, *unkindness* appears as carelessness, the product of a lack of curiosity and connection and a lack of awareness of her expertise.

*Unkindness* is not always accidental or unthinking; in Rosie's story, it is overt and direct. Rosie has 'fought' for everything for her son from the moment he was born. Her relationship with practitioners is fraught. She has been called 'a liar' by social services. She explains that social services 'attacked' her and said that she had 'invented everything' about her son's difficulties and diagnoses. She told us they had 'kicked' her when she was 'down'.

### *(Un)Kind systems and practices*

We suggest the inflexibility of systems and processes enables or encourages spaces in which *kindness* can be disavowed with little consideration or reflection. Professionals can utilise the concept of 'the system' to remain disconnected from people's lives and reinforce and enact practices that, while seemingly in line with 'system rules', can be a denial of their own moral autonomy. We found little shaping of a *kinder* world or evidence of the importance of being curious about and interested in people's lives and experiences. Janet, for example, described finding the process of gaining direct payments, which involved having to sit and listen to someone reading the notes to them for two hours a week, for six weeks, too stressful and controlling to cope with. They described how 'sometimes things become inflexible, either intentionally or unintentionally'.

This disavowal of *kindness* generates and allows disrespectful engagement. For Entwistle et al (2024), writing in relation to healthcare, disrespect demonstrates the failure to relate to people as equals, which brings us back to social injustice. We found myriad examples of what participants recount as disrespectful encounters:

The council, the social services... 'Well, we didn't manage to get him off our books that way, so we'll get him off this way' or 'We'll try the next route'. It's almost as if they are systematically going through a list of, 'How can we avoid our legal duty to help this family?' And we're literally up against it all the time. (Rosie)

One of the stresses for us as carers is when the social workers and the professionals disappear and you're not told that they've gone, and then six months down the line, you suddenly find out, 'Oh, well, where's my social worker? Oh, she's gone'. You know, it's nice to say thank you to them, to say goodbye rather than just have them disappear. (Janet)

Relationships are severed without warning, demonstrating the lack of value attached to those relationships. They are transactional relationships designed to offer incurious engagement with carers rather than relationships that have the potential to nurture and nourish, and this permits cruelty. Instead of Haraway's (2015) expansive and worlding ties of *kinship*, a disassemblage of divisions, of otherness, is generated and sustained over time.

The reification of 'the system' is further presented as the stumbling block to accessing appropriate care or *kindness*: 'It's the system. There's just no care; there's just no

compassion' (Chris); 'System is the easiest answer because, unfortunately, the system as it is at the moment, everybody has to fit the system, whereas the system should fit the person' (Steven). Through erasing space for *kindness*, we can see how carers simply do not matter and, consequently, conditions are created for the acceptance of unacceptable or even abusive practices. Professionals are emboldened to become ever more disconnected bystanders. We identified a sense of menace felt by participants around the power of the professionals within these systems. Rosie described being threatened that their son would be taken away if they did not agree to cuts in their social care support. Caitriona described a similar fear of losing their child through actions she described as 'emotional terrorism':

About four years ago, I was approaching yet another one of the dreaded assessments, you know, and we are always living in fear of them either removing, continuing healthcare or, worse still, putting her into residential care. And they never fail to let me know that this is a possibility, you know, which I find is emotionally terrorism because they have letters from every single doctor, GP [general practitioner], consultant, ex-nurse and current nurse saying that it would actually endanger her life and the best possible situation is what she has now. (Caitriona)

People are differentially positioned within this system depending on such characteristics as class, ethnicity, age and ability, and some are better placed to access support and resources. Resource-rich carers may generate a better outcome for their relatives, instrumentally making gains that others cannot. Kristina, who also worked with adults with learning disabilities, described 'being lucky' because they knew how the system worked and who to email. Caitriona described a long battle with healthcare providers over her daughter's diagnosis that extended to threats of court action over switching off her life-support machine. This changed when her partner's academic status emerged through his knowledge about the angle of their daughter's feeding tube:

All of a sudden, when they realised, 'Oh, this guy's an academic', they suddenly allowed us to have a second opinion because it was the Old Boys Club. So, you can imagine my fury because it didn't seem to matter what evidence I threw at that; I even asked them to ring her consultant in [country], but they refused us that up until that point. (Caitriona)

We might assume *kindness* could emerge when invisibility is lifted in these moments, that assumed familiarity and connection between professionals and carers may allow a reassembling of kin. However, Caitriona described her anger at not being listened to, at not being treated with respect as an equal.

### *Cursory health and social care*

Parents shared stories of seeking support for their mental health. However, rather than stories of care or *kindness*, their accounts involved invisibility and what could be described as cursory care. The diagnosis, treatment and/or support offered failed

to align with their experiences or acknowledge their caring role. Janet was adamant that while she had the symptoms of depression, she was experiencing severe stress, without the depression bit', and yet the doctor 'always goes to, sort of, the traditional explanations of, "This is depression. Oh no, you're depressed"'.

Chris similarly explained how they went to the doctor for help as they 'just felt an emotional wreck'. They wondered if this was down to the menopause, being a carer or a combination of both but described how the doctor failed to ask questions about their caring role, their support networks or what might help. As they were not experiencing hot flushes, the doctor concluded that antidepressants were required. While it appears care was present as 'treatment' was offered, for Chris, the encounter lacked understanding, *kindness* and compassion: 'Just antidepressants, and that was it, yeah. So, no understanding there at all. And, I don't know, I think that's what you want sometimes, just for someone to have a bit of understanding. It is that kindness, that compassion that doesn't seem to exist a lot of the time.'

We suggest that these absences, this cursory care, speak to a lack of curiosity on the part of professionals. Curiosity would necessitate questions, an interest in understanding more about the person and their caring role, and how this may affect their mental health or the effectiveness of available treatment. This lack of curiosity could be experienced as a lack of listening and a homogenisation of experiences:

I mean, the first problem with the authorities is listening; they're not very good at listening. They think they're very good at telling people, but they're hopeless at that as well. And they seem to view that one carer is like another carer, and what a carer does one day is exactly the same for the next. I mean, it's not. (Steven)

In failing to be curious within these encounters, professionals exacerbate the invisibility of carers by abstaining from fostering connections. Lisa, for example, said that in 20 years of caring, the GP has never asked about this role and the impact it may have on their lives, a lack of curiosity that extended to their own identity as an autistic person:

Just that they forget it. So, they forget that things may affect me in a certain way. Or, if I attend a meeting, it's going to affect me in a certain way. Or, they don't see that some of the things that happen to my son are likely to have a traumatic impact on me, perhaps more so than they might have on someone else. (Lisa)

In a familiar example to many carers (Nimmo, 2019), Katrin described being 'called "Mum" a lot: "So, Mum ..." from whoever it is, the consultant or whoever it is that we are seeing'. This explicit form of othering does not allow for recognition of the knowledge, experience and understanding of the carer (Nimmo, 2019), instead creating conditions that work against the development of connections. In keeping kinship at bay, encounters with professionals remain spaces where cursory or even careless care is the norm, where there is no 'you have me, I have you, we have each other' (Haraway, 2022). Professionals can act without regard for the distress they may cause in their failure to address the person's mental health. In the absence of accountability generated through kinship, professionals can indeed 'just walk away from it' (Haraway, 2022).

## Speculative fabulations of curious *kindness*

Here, we set to work with Haraway's concept of speculative fabulations as a mode of countering the *unkindness* and absences of *kindness* that have entangled with so much of this article and the narratives of carers with which it has been constructed (Haraway, 2022). We are drawn to writing experimental fabulations as a means for analytical engagement with the *kindness* that is woven through the narratives of carers, as this particular mode of writing always involves the inclusion of a question (Haraway, 2022). In this context, the questioning is always around curious *kindness* and what it does in the lives of carers as kin. Speculative fabulations do more than speculate what could be; they draw attention to that which already exists but make it even greater, even more powerful than imagined (Haraway, 2022).

A curiosity of *kindness*, when understood as we have conceptualised it, steeped in strengthening ties of kinship that are built upon knowing more about a person after the encounter than before, glimmers in the data. To 'get someone' becomes a part of becoming curious; you cannot, we argue, really 'get' someone without paying curious attention to their lives:

She really got me, do you know what I mean? She wasn't like, 'Oh, I've got somebody else to see after you, so you'll have to hurry up', and she really listened and she took time. I don't know, I think for the first time, I felt that I was being listened to, in all my years, I was listened to, and that was priceless. (Julie)

The 'getting it' offers a glimmer of speculative and much-needed counter-fabulation to the enduring dominant narratives of fighting for services and support that permeate the lives of carers (Smith et al, forthcoming): 'Health – fantastic; they're absolutely brilliant. He needs, he gets. We assess him, and they literally throw it at us. 'Yeah, he needs this, he's complex, he has this, he has that' (Rosie).

Part of the 'getting' kin as *kind* entangles with an expansive, curious concept of listening that expands beyond simply paying attention to what is being shared or acting upon what has been heard (McLeod, 2006). A curious concept of listening is one that entangles listening as an accountable interactive process whereby connections are strengthened and actions are responsive to what is not only heard but also deeply understood after the encounter (Philips, 2016):

I mean, there's been some instances when it wasn't so good, but at least that care provider was prepared to listen, which unfortunately, well, I was going to say not many do, but a certain number don't. And then they were providing carers who they thought would fit into our situation, and if they didn't, then they said, 'Fine, we'll find somebody else', which again is highly unusual. (Steven)

*Kindness* enfolds as connections strengthen through encounters that actively demonstrate a curiosity as a proactive willingness and desire (through the expressed excitement in the following excerpt) to learn what is needed beyond what might already be known, a curiosity enfolding knowledge and professional learning:

There are very helpful people out there that will, sort of, come along. We had a very good social worker for one year. I mean pretty much.... Well, they're pretty good most of the time. For one year, we had one that had come from adult services, so she didn't understand children's service much, but she would look up information and phone me and say, 'I've got this, I've got this', and then we would talk about, 'Do you know about this as well?'. And she got really excited, and it was so brilliant to have that kind of relationship where we could share information with each other and pass it on. (Janet)

This expansive conceptualisation of curious listening diffuses the panic and fear that ripple through the following extract. Meeting fear and panic with a curious *kindness* diffuses the fear and offers active desire for connection and kinship:

And then they got somebody from mental health to come and see me, and then I panicked because I thought, 'Oh no', because I've been an outpatient before in the past and I thought, 'Oh', the first thing I said when they sent the person down was, 'You're not putting me away, you're not putting me as an inpatient'.... But I was really lucky that this chap was really good and said, 'No, no, I'm not going to do that; I'm more interested in what's happened to you and what's wrong with you', which was the other way round to my previous experiences. So, that was good. (Lisa)

Our final fabulation is one that emphasises the importance and power of *kindness* of human connections that transcend the power imbalances of roles and titles and the welcome inclusion of finding shared experiences of human life (Haraway, 2016): 'The GP said, "I'll be honest"; she said she herself has a disabled child, and she said, "I know where you're coming from". And it's like, "Wow". And she's been very, very good. She does phone me up occasionally and say, "How are you? What's happening?"' (Rosie).

## **Concluding with hope for *kindness***

We began this article by thinking about both the presence of *kindness* and its *absence*. In our readings and rereadings, we looked for *kindness* and found ourselves repeatedly distracted by disconnection and disrespect. We continued in the hope of finding *kindness*. While continuing to hope is risky, the need for hope and for fabulating the importance of the *kindness* that does already exist, alongside the *unkindness* and absences of *kindness*, is urgent in times of ongoing injustices in the lives of carers and people with learning disabilities (Haraway, 2022). We do not want to be seen as 'Pollyanna' about this; our hopefulness does not depend on having to avert our gaze from the daily experiences of people's lives (Lear, 2006). However, we do want to hold onto hope, writing speculative fabulations of hope and kindness as 'the belief in the possibility of a better future, and thus our sense that our efforts to "make a difference" might be worthwhile' (Edgoose, 2009: 106).

We have found moments of connection and *kindness* in the carers' stories about their lives, moments greater than the sum of their encounter as they weave *kindness* through this article and beyond as a mode of recognising that which is already there and can be expansively nurtured (Haraway, 2022). Above all, carers valued being listened to, and this is something that all those entangled professionally in the lives of

carers can nurture (Haraway, 2022). Carers wanted to be ‘heard and seen ... celebrated, not ignored or hidden away’ (Katrin), a curious *kinship* invoked and invited. Carers understood the importance of people remaining curious about their lives in order for connections to be made and for them to benefit from *kindness*:

It’s important for people to understand what caring is about. I just don’t think people realise how hard it is, and I think the more you can get that message out and the more we can have some kindness and compassion from others, then I think it would help everyone really. (Chris)

Listening, curiously and responsively, to carers and people with learning disabilities in order to understand more about their lives and their needs demands an enfolding of *kindness* and compassion:

But he’s got a good RC [responsible clinician]; the first RC was horrendous. This [second] RC is actually the opposite [of the first], a really good, kind, compassionate man. Because [Name] was put in the HDU [high dependency] unit on his own ... so he was put in there on his own because he wouldn’t be safe with the other patients. Because my son has got a severe learning disability ... some of these patients have come through the forensic route, and we knew he wouldn’t be safe there, he [the responsible clinician] knew that. (Lisa)

People knew that systems and services are under pressure; they were not ‘asking for millions’ (Rosie), but seemingly small acts of *kindness* made a big difference in people’s lives. These small acts, when embraced, offer threads of hope for better practices and relationships with carers and people with learning disabilities (Haraway, 2022). Unsurprisingly, where people already had an experience or understanding of the lives of carers and people with learning disabilities, it was easier to make a connection and to be *kind*:

The GP said, ‘I’ll be honest’; she said she herself has a disabled child, and she said, ‘I know where you’re coming from’. And it’s like, ‘Wow’. And she’s been very, very good. She does phone me up occasionally and say, ‘How are you? What’s happening?’ And it’s, sort of, I’m alright, caring for [Name]. I do it with my eyes closed; it is a parent’s love, duty. But I’m dead on my knees. (Rosie)

Carers learn not to expect *kindness* in their engagement with services, families and their communities; disconnection from kin leaves carers carrying heavy responsibilities in isolation and alone. We invite an ongoing engagement with curious *kindness* for kinships to strengthen services and support in the lives of carers and people with learning disabilities. The *kindness* is there but needs to be appreciated and nurtured beyond that which already exists (Haraway, 2022).

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The authors declare that there is no conflict of interest.

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