



This is a repository copy of *Kindness and curious kinships in the lives of family carers of adults with learning disabilities*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/227634/>

Version: Accepted Version

Article:

Ribenfors, F., Smith, M. orcid.org/0000-0003-2499-4241, Runswick-Cole, K. et al. (1 more author) (2025) Kindness and curious kinships in the lives of family carers of adults with learning disabilities. *International Journal of Care and Caring*. pp. 1-18. ISSN 2397-8821

<https://doi.org/10.1332/23978821Y2025D000000128>

© 2025 The Author(s). Except as otherwise noted, this author-accepted version of a journal article published in *International Journal of Care and Caring* is made available via the University of Sheffield Research Publications and Copyright Policy under the terms of the Creative Commons Attribution 4.0 International License (CC-BY 4.0), which permits unrestricted use, distribution and reproduction in any medium, provided the original work is properly cited. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here: <https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Introduction

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

This paper 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 with and coproduced 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., 2004a; 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, 2017). In doing so, this paper contributes to the growing literature which 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 (Goodey, 2015; Simpican, 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, 2024 a,b; Smith et al, forthcoming). Throughout this paper, 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 emphasises 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 and, therefore, as 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’ or something that must be ‘felt’; it is a social justice issue and, as we argue below, there is ‘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, and 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 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 as “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’ (DoH, 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 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 to explain it in terms of sympathetic identification with the vulnerabilities of others, and the intervention into the life of another’ (Hamrick 2002:64). 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 lack of connection can promote disrespect in services 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 wellbeing - 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, 2003:928) 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 (Grootegoed 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, 2007). 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, 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 paused 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 and 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,b). 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 they want to be listened to, understood and valued as carers (Runswick-Cole et al,

2024a,b). To become responsible to 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 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: online)

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 paper. 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, 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 we are ours and we are implicated in whether we choose to be *kindly* curious to 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 paper, 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 6 phases: (1) The recruitment of a public involvement group comprising 5 carers, 4 adults with learning disabilities and 3 university researchers. The group 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, 2024); (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); (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 paper reports on the parent carer interviews from Phase 4 of the project (n=12). MacLure (2013) talks about data that draws you in and seizes your attention as data that 'glows'. She goes on to argue that the 'wonder' that data produces 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 was generated from twelve parent carers of adults with learning disabilities between August 2023 and January 2024. Carers were recruited via project social media accounts on Twitter, Instagram, LinkedIn and Facebook and via project public involvement group and steering group networks. Participants resident in the UK who identified as carers of adults with learning disabilities over the age of eighteen were included in the study.

[TABLE 1 HERE]

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 was generated via online 1-1 interviews using Zoom.

Interviews were audio recorded and professionally transcribed. Transcriptions were anonymised and returned to participants for approval and as an opportunity for making 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 and 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 this was more accessible. We transferred data from Zoom to the University's secure drive as soon as possible after the interviews.

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 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 re-reading them whilst 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 seeking narrations of togetherness, collectively 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 re-read the transcripts pulling out relevant extracts and grouping them according to these areas. Further discussion amongst the four authors and a re-grouping 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 re-told as if it happened yesterday. She describes the moment when she arrived, with her son, for an appointment with the orthotist. Her son wore Pedro 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 begins 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 has been in a swimming lesson and, afterwards, school staff helped him to dress. 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 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, which permit 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 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 to be 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.

Rosie: 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.

Janet: ...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 6 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.

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*.

Chris: It’s the system. There’s just no care, there’s just no compassion.

Steven: 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.

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';

Caitriona: About 4 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, consultant, ex-nurse and current nurse saying that it would actually endanger her life and the best possible situation is what she has now.

People are differentially positioned within this system depending on characteristics such 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 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:

Caitriona: 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.

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 antidepressants were required. Whilst it appears care was present as ‘treatment’ was offered, for Chris the encounter lacked understanding, *kindness* and compassion:

Chris: 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 these absences, this cursory care, speaks 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:

Steven: 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.

In failing to be curious within these encounters, professionals exacerbate the invisibility of carers by abstaining from fostering connections. Lisa, for example, said 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:

Lisa: 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.

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: online). 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: online)

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 paper 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.

Julie: 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.

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):

Rosie: 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'.

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, actions are responsive to what is not only heard but deeply understood after the encounter (Philips, 2016).

Steven: 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.

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

Janet: 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.

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

Lisa: 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.

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):

Rosie: 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'.

Concluding with Hope for *Kindness*

We began this paper by thinking about both the presence of *kindness*, and *its absence*. In our readings and re-readings we looked for *kindness* and found ourselves repeatedly distracted by disconnection and disrespect. We continued in the hope of finding *kindness*. Whilst 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). But 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 paper 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 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 to their lives in order for connections to be made and for them to benefit from *kindness*.

Chris: 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.

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

Lisa: ... 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.

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*.

Roise: And 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 you know it all comes out and it's sort of 'absolutely fine'. She said 'are you alright, are you alright?'. And it's sort of I'm alright, caring for [Name] I do it with my eyes closed, it is a parents' love, duty. But I'm dead on my knees.

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).

Funding

This paper is part of the 'Tired of spinning plates: an exploration of the mental health experiences of adults/older carers of adults with learning disabilities' project, funded by the National Institute of Health and Care Research (NIHR) Health and Social Care Delivery Research (HSDR) Project (NIHR135080). The views expressed are those of the authors, not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Conflicts of Interest

The Authors declare that there is no conflict of interest

References

- Atkinson, R. (2019) The murder box: a trope for inhumanity, Paper presented at Humanity Under Duress, The University of Sheffield, 20-21st June, 2019, Sheffield, United Kingdom.
- Bach-Mortensen, A., Goodair, B. & Corlet Walker, C. (2024) A decade of outsourcing in health and social care in England: What was it meant to achieve?. *Social Policy & Administration*. 1-22. DOI:10.1111/spol.13036
- Berlant, L. (2007) Slow Death: Sovereignty, Obesity, Lateral Agency. *Critical Inquiry* 33(4), 754-780. DOI:10.1086/521568
- Brownlie, J. and Anderson, S. (2017) Thinking sociologically about kindness: puncturing the blase in the ordinary city, *Sociology* 5(6), 1222-1238. DOI:10.1177/0038038516661266
- Buetow, S. (2013) Physician kindness as sincere benevolence, *Canadian Medical Association Journal* 185(10), 928-928. DOI:10.1503/cmaj.121457
- Clegg, S., and Rowland, S., (2010) Kindness in pedagogical practice and academic life, *British Journal of Sociology of Education*, 31(6), 719-735, DOI:10.1080/01425692.2010.515102
- Cluley, V. (2018) From "Learning disability to intellectual disability"—Perceptions of the increasing use of the term "intellectual disability" in learning disability policy, research and practice. *British Journal of Learning Disabilities*, 46(1), 24-32. DOI:10.1111/bld.12209
- Curry, O. S., Rowland, L. A., Van Lissa, C. J., Zlotowitz, S., McAlaney, J. & Whitehouse, H. (2018) Happy to help? A systematic review and meta-analysis of the effects of performing acts of kindness on the wellbeing of the actor. *Journal of Experimental Social Psychology*, 76, 320-329. DOI:10.1016/j.jesp.2018.02.014
- Department of Health (DoH) (2012) *Transforming care: A national response to Winterbourne View Hospital: Department of Health Review Final Report*. London: Department of Health.
- Douglas M. (1966) *Purity and Danger*. London: Routledge.
- Douglas, P., Rice, C., & Kelly, C. (2017) Crippling care: Care pedagogies and practices. *Review of Disability Studies: An International Journal*, 13(4) Available from: <https://www.rdsjournal.org/index.php/journal/article/view/779/1856> [Accessed April 2024].
- Eales, L. and Peers, D. (2021) Care haunts, hurts, heals: The promiscuous poetics of queer crip Mad care. *Journal of Lesbian Studies*, 25(3), 163-181. DOI:10.1080/10894160.2020.1778849
- Edgoose, J. (2009) Radical hope and teaching: Learning political agency from the politically disenfranchised. *Educational Theory*, 59(1), 105-121. DOI:10.1111/j.1741-5446.2009.00309.x
- Entwistle, V.A., Cribb, A. and Mitchell, P. (2024) Tackling disrespect in health care: The relevance of socio-relational equality. *Journal of Health Services Research & Policy*, 29(1), 42-50. DOI:10.1177/13558196231187961
- Epstein, A. (2013) Not just words: Caring for the patient by caring about language *JAMA Internal Medicine*. 173(9) 727-728 DOI:10.1001/jamainternmed.2013.365

- Faust, H. (2009) Kindness, not compassion, in healthcare, *Cambridge Quarterly of Healthcare Ethics*, 18(3), 287-299. DOI:10.1017/S0963180109090458
- Fritsch, K. (2010) Intimate assemblages: Disability, intercorporeality, and the labour of attendant care. *Critical Disability Discourses*. Available at: <https://cdd.journals.yorku.ca/index.php/cdd/article/view/23854> (Accessed: 24 April 2024).
- Goodey, C.F., (2015) *Learning disability and inclusion phobia: Past, present, future*. London: Routledge DOI:[10.4324/9780203556658](https://doi.org/10.4324/9780203556658)
- Goodley, D., Liddiard, K., & Runswick-Cole, K. (2018). Feeling disability: Theories of affect and critical disability studies. *Disability & society*, 33(2), 197-217.
- Grootegeod, E., and Smith, M., (2018) The emotional labour of austerity: how social workers reflect and work on their feelings towards reducing support to needy children and families, *The British Journal of Social Work*, 48(7), 1929-1947 DOI:[10.1093/bjsw/bcx151](https://doi.org/10.1093/bjsw/bcx151)
- Habibis, D., Hookway, N. & Vreugdenhill, A. (2016) Kindness in Australia: an empirical critique of moral decline sociology, *British Journal of Sociology*, 67(3), 395-413. DOI:10.1111/1468-4446.12194
- Hamington, M. (2018) The care ethics moment: international innovations. *International Journal of Care and Caring*, 2(3), 309–18. DOI:10.1332/239788218X15366790166525
- Hamrick, W. (2002) *Kindness and the good society*. New York: State University of New York Press.
- Haraway, D. (2008) *When Species Meet*. Minneapolis: University of Minnesota Press.
- Haraway, D. (2015) Anthropocene, Capitalocene, Plantationocene, Chthulucene: Making Kin. *Environmental Humanities*, 6(1), 159-165. DOI:10.1215/22011919-3615934
- Haraway, D. (2016) *Staying with the Trouble*. Durham and London: Duke University Press.
- Haraway, D. (2022) <https://nextnature.net/magazine/visual/2022/donna-haraway>
- Hill, D., and Laredo, E., (2020) The personal is political: reframing individual acts of kindness as social solidarity in social work practice, *European Journal of Social Work*, 23:6, 969-979 DOI:10.1080/13691457.2020.1805587
- Hochschild, A. (2000). Global care chains and emotional surplus value. In W. Hutton & A. Giddens (Eds.), *On the Edge: Living with Global Capitalism* pp130-146. London: Jonathan Cape.
- Hughes, B. (2019) Invalidating emotions in the non-disabled imaginary. Fear, pity and disgust in N. Watson. and S. Vehmas. (eds) *Routledge Handbook of Disability Studies*, 2nd ed. Milton: Routledge. DOI:10.4324/9780429430817
- Hughes, B., McKie, L., Hopkins, D. and Watson, N. (2005) Love's labours lost? Feminism, the disabled people's movement and an ethic of care. *Sociology*, 39(2), 259-275.
- Jeffrey, D. (2016) A Duty of Kindness. *Journal of the Royal Society of Medicine*, 109(7), 261-263. DOI:10.1177/0141076816643333
- Johnstone, M.J. (2010) On the matter of human kindness. *Australian Nursing and Midwifery Journal*, 17(7), 32.

Lear, J. (2006) *Radical Hope: Ethics in the Face of Cultural Devastation*. Cambridge, Mass.: Harvard University Press.

Macchiavello, C. (2015) Caring, curiosity and curating, beyond the end. Available from: <https://www.seismopolite.com/caring-curiosity-and-curating-beyond-the-end> [Accessed 18 June 2024]

McEvoy, P. and Plant, R. (2014) Dementia care: Using empathic curiosity to establish the common ground that is necessary for meaningful communication. *Journal of Psychiatric and Mental Health Nursing*, 21(6), 477-571. DOI:10.1111/jpm.12148

MacLure, M. (2013) The Wonder of Data. *Cultural Studies ↔ Critical Methodologies*, 13(4), 228-232. DOI:10.1177/1532708613487863

Magnet, S., Mason, C. L., and Trevenen, K. (2014) Feminism, pedagogy, and the politics of kindness. *Feminist Teacher*, 25(1), 1-22. DOI:10.5406/femteacher.25.1.0001

Mallett, R., and Runswick-Cole, K. (2014). *Approaching Disability: Critical Issues and Perspectives*. Routledge.

Minh-ha. T. T (1988) Not you/like you: Post-colonial women and the interlocking questions of identity and difference. *Feminism and the Critique of Critical Discourse*, Inscriptions 3-4. Available from: <https://culturalstudies.ucsc.edu/inscriptions/volume-34/trinh-t-minh-ha/> [Accessed 4 May 2020].

Morris, J. (1997) Care of empowerment? A disability rights perspective. *Social Policy & Administration*, 31(1), 54-60. DOI:10.1111/1467-9515.00037

Nimmo, S. (2019) Please don't call me mum. *BMJ (Online)*, 367, l5373-l5373. DOI:10.1136/bmj.l5373

Nishida, A. (2022) *Just Care: Messy Entanglements of Disability, Dependency, and Desire*. Temple University Press.

O'Hara, M. (2015) *Austerity Bites: A Journey to the Sharp End of Cuts in the UK*. Bristol: Policy Press

Phillips, A., and Taylor, B. (2009). *On Kindness*. London: Penguin Books Ltd.

Philips, R. (2016) Curious about others: relational and empathetic curiosity for diverse societies. *New Formations: A Journal of Culture/Theory/Politics*, 88, 123-142. DOI:10.3898.NEWF.88.02.201

Rowland, S. (2009) Viewpoint: Kindness. *London Review of Education*, 7(3), 207-210. DOI:10.1080/14748460903290272

Runswick-Cole, K., Smith, M., Ryan, S. and Hatton, C. (2024a) 'Should we even have questions?' From survey to exhibition – co-producing research about 'mental health' with carers and adults with learning disabilities, *International Journal of Care and Caring*, 1-16, DOI:10.1332/23978821Y2024D000000051

Runswick-Cole, K., Smith, M., Ryan, S., & Douglas, P. (2024b). Dis/Entangling Disability, Mental Health, and the Cultural Politics of Care. *Scandinavian Journal of Disability Research*, 26(1), 28-43

Runswick-Cole, K., Douglas, P., Fogg, P., Alexander, S. Ehret, S., Eves, J., et al.. (2024c) When Father Christmas is the Gaslighter: how special education systems make (m)others mad, *Journal of Cultural and Literary Disability Studies*

Ryan, S. (2017) *Justice for Laughing Boy*, London: Jessica Kingsley Publishers

Simplican, S.C., (2015) *The Capacity Contract: Intellectual Disability and the Question of Citizenship*. University of Minnesota Press.

Smith, M., Runswick-Cole, K., Ryan, S., Hatton, C., Douglas, P., Croot, L., et al., (forthcoming). Tired of Spinning Plates? A Rapid Scoping Review of the Mental Health Needs and Mental Health Support of Carers of Adults with Learning Disabilities in the United Kingdom. *International Journal of Disability and Social Justice*.

St Pierre, E.A. (2018) Writing post qualitative inquiry. *Qualitative Inquiry*, 24(9), 603-608

Taguchi, H.L. and St. Pierre, E.A. (2017) Using concept as method in educational and social science inquiry. *Qualitative Inquiry*, 23(9), 643-648. DOI:10.1177/1077800417732634

Tanner, D. (2020) 'The Love That Dare Not Speak Its Name': The Role of Compassion in Social Work Practice, *The British Journal of Social Work*, 50(6), 1688–1705, <https://doi.org/10.1093/bjsw/bcz127>

Ward, N. (2011) Care Ethics and Carers with Learning Disabilities: A Challenge to Dependence and Paternalism. *Ethics and Social Welfare* 5(2) 168-180
DOI:10.1080/17496535.2011.571066

Willis, E. and Kavka, A. (2021) Editorial: The Politics and Practices of Kindness. *Knowledge Cultures*, 9(3), 7-19. DOI:10.22381/kc9320211