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Mindful Together Project Final Report

August 2026

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Funded by Pears Foundation

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Acknowledgements

We would like to acknowledge the support of the project funders, the Pears Foundation, without which this project would not have been possible.

We would like to thank all of the family carer participants who took part in this project, and all of the project peer mentors for working on this project. We would also like to thank the Foundation for People with Learning Disabilities for recruiting and managing the peer mentors, and we thank Christine Burke for her work in setting up this project. Thanks also to the charity partners for working with us, especially individuals not named as authors of this report: Gail Walshe and Gail Bedding from Contact; Rhian Allman and Rachael Greene, formerly of Family Fund. We would also like to thank Alison Baker and Diana Smith for providing administrative support for this project, and Katharina Bucher for support during data collection.

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Executive Summary

- The University of Warwick team worked closely with four project partners (Sibs, Family Fund, the Foundation for People with Learning Disabilities (FPLD), and Contact) to complete an implementation project of an online mindfulness programme (Be Mindful) with additional peer mentor support for family carers of people with learning disabilities and/or of autistic people with the aim of reducing their stress and increasing their wellbeing.
- A team of ten parent and five adult sibling peer mentors were successfully recruited through project partners and trained to deliver the peer mentoring element of the project. They were successfully matched with family carers throughout the project period.
- The University team completed an evaluation of the project, including questionnaires with family carer participants before and after they started the intervention, and again 12-weeks later, interviews with peer mentors, and interviews with some family carer participants.
- We were particularly successful in recruiting siblings to be peer mentors, and to take part in the intervention; however, we recruited fewer brothers than sisters. Successfully recruiting and engaging brothers is an area for exploration in future.
- When interviewed, peer mentors described having overwhelmingly positive and meaningful experiences within their role. Further, peer mentors were able to develop transferable skills for future employment, which contributed to their reported increased confidence.
- Family carers reported experiencing a wide array of benefits from their engagement in the mindfulness programme and peer mentoring, including improved wellbeing, greater acceptance and reflection within their caring role and about themselves, benefits to family, and improved relationships.
- Some of the difficulties faced in recruiting family carers to this project may be due to renewed interest in receiving face-to-face support and fostering a sense of community for family carers following the necessity of online/virtual support during the COVID-19 pandemic and related restrictions.
- The reflections from the University team and the project partners to inform future projects include having a more inclusive peer mentor application process, running separate training sessions for parent and sibling peer mentors, having a translation budget for materials, and specifically recruiting peer mentors who speak additional languages to promote inclusion of family carers who speak English as an additional language.

1 Background

The Mindful Together project (November 2021-April 2024), funded by the Pears Foundation, was an implementation project of a mindfulness intervention for family carers of people with learning disabilities and/or of autistic people (*henceforth referred to as family carers*) with the aim of reducing stress/increasing wellbeing.

Family carers report positive experiences in their roles as carers; however, they are often at an increased risk of mental health problems and stress. Family carers play an important role in the lives of their families and society. Therefore, it is important to identify appropriate supports for family carers.

The Mindful Together intervention for family carers consists of two components:

1. Free access to Be Mindful, an online, evidence-based, mindfulness programme developed for the general adult population.
2. Three telephone mentoring sessions delivered by other, trained, family carers (*henceforth referred to as peer mentors*) to support family carers to engage with, and complete, Be Mindful.

This model was developed and tested previously in a randomised controlled trial[1]. The findings from this previous research suggested that the addition of peer mentoring alongside the Be Mindful programme added value for family carers and may have improved their outcomes in terms of better well-being.

1.1 Aims of the Mindful Together project

A key challenge related to research evidence is that it takes a long time to, or fails to, influence practice and benefit families. Mindful Together was established to begin addressing this gap and was informed by, and extended the work from earlier research in the following ways:

1. Mindful Together was an implementation project in which we planned to deliver Be Mindful and additional peer mentor support to a larger group of family carers and learn from this implementation.
2. We planned to include adult sibling carers as well as parent carers and ringfenced 50 of the 150 available places on the project for sibling carers.
3. A University team worked with partner organisations (Sibs, Family Fund, the Foundation for People with Learning Disabilities (FPLD), and Contact) to support recruitment of key groups of family carers who are less likely to receive supports and were under-represented in the earlier research (and are typically under-represented in other research).

[1] Flynn, S., Hastings, R. P., Burke, C., Howes, S., Lunsky, Y., Weiss, J. A., & Bailey, T. (2020). Online mindfulness stress intervention for family carers of children and adults with intellectual disabilities: Feasibility randomized controlled trial. *Mindfulness, 11*, 2161–2175. https://doi.org/10.1007/s12671-020-01436-0

4. To carry out an evaluation of the project, we gathered questionnaire data before family carers started Be Mindful and after they had been through the programme. We also interviewed some family carers and peer mentors about their experience of the project.

2 The project

2.1 Be Mindful Programme and Additional Peer Mentor Support

Be Mindful is an online mindfulness programme developed by Wellmind Health (https://www.bemindfulonline.com/), with 10 online sessions based on mindfulness-based cognitive therapy (MBCT), 12 assignments to practice in daily life, six course handouts, and supporting emails throughout. The programme is publicly available and can be accessed on any device with a web browser and an internet connection.

Ten parent and five adult sibling peer mentors were recruited to the paid role through project partners. Peer mentors attended a 1.5-day virtual training workshop and completed Be Mindful themselves before being matched with their first family carer. Peer mentors were matched with family carers based on role (i.e., parent or sibling) and availability, with age of the person they cared for (i.e., child or adult) also considered where possible.

Family carers were offered three 30-minute telephone calls from a peer mentor in addition to free access to Be Mindful. During telephone calls, peer mentors followed a coproduced 'manual' developed in an earlier research project that described the purpose and content of the sessions. The focus of the calls was to encourage and support family carers in their progress with Be Mindful. Family carers had their first peer mentor call before starting Be Mindful online. Two further telephone calls were offered by peer mentors to all family carers at intervals during their completion of Be Mindful.

2.2 Project evaluation

A brief overview of what we did in this project is outlined below, and more detailed descriptions are presented in the three academic journal papers prepared from the project (Links provided in the Appendix).

Family carers were 43 adult sibling and 58 parent carers who responded to targeted recruitment advertisements via charity partners, support groups, and social media. All family carers completed a short screening form to ensure that they were eligible for the project. The only exclusion criterion for this project was if family carers had already accessed the Be Mindful programme.

Family carers were asked to complete a short questionnaire before their first peer mentor telephone call, and again 12 weeks after they started the intervention. The questionnaires included questions about the family carers, the person they care for, the family carer's wellbeing, psychological distress, life satisfaction, and their perceptions of their family's functioning.

Some family carers and peer mentors were also invited to take part in an interview about their experiences of the project, Be Mindful, and peer mentoring.

3 Summary of findings

Full findings from the project are described in detail in three academic journal papers produced from the project. The links to these papers are included in the Appendix to this report (1. A brief report of the quantitative findings; 2. A qualitative study of peer mentor experiences; 3. A qualitative study of family carer experiences that includes pooled data from the current project and an earlier research study).

3.1 Summary of questionnaire findings

We were able to successfully recruit a wide group of family carers, including adult siblings and family carers whose weekly household income was below the UK median. Most family carers who had access to Be Mindful and the telephone peer mentor support calls did not complete the intervention during the project period, but 81.8% of family carers who did complete Be Mindful before the end of the project also received all three telephone peer mentor support calls. Sibling carers were more engaged with the intervention in this project than parent carers were. Although follow-up questionnaires were not completed by all family carers, analysis of the follow-up data suggested that there were improvements in psychological wellbeing for family carers over time associated with receiving Be Mindful.

3.2 Summary of findings from the peer mentor interviews

Peer mentors described overwhelmingly positive experiences of mentoring other family carers, noting that the experience was meaningful and enjoyable for them. They believed that they had, within their role, made a difference to the family carers who they mentored. The shared understanding between family carers and peer mentors facilitated their mentoring relationships but could also lead to difficulties maintaining boundaries in the role. As well as valuing being in paid employment that was meaningful for them, peer mentors were able to develop skills and experience personal growth through their engagement in the roles; and this was a key mechanism in increasing their confidence.

3.3 Summary of findings from the family carer interviews

Family carers were not always able to embed the mindfulness practices in their lives as intended but were able to adapt their learning to ensure that they could "fit" mindfulness in with their lives and needs. Having limited time or prioritisation for themselves and expecting more from the peer mentoring role than was offered impacted how family carers perceived the programme. Perceived direct benefits included improved wellbeing, paying attention to physiological stress responses, greater acceptance, and reflection. Indirect benefits, which were sometimes recognised on their own but mostly as part of a process starting with the direct benefits, were benefits to family and improved relationships.

4 Learning and Reflections

4.1 Collaboration between the University team and charity partners

The University team formally collaborated with four organisations. The main project partner was the **Foundation for People with Learning Disabilities (FPLD)**, who were the implementation team responsible for the delivery of the peer mentoring programme. Regarding the collaboration, our contact at the FPLD stated that:

> *'Working collaboratively with colleagues at the University of Warwick has been excellent…Working with the peer mentors has also been thoroughly enjoyable. The group are engaged and knowledgeable, and communication is excellent.'*
>
> David Mahon, FPLD

As the FPLD collaborated with the University on the previous research, this connection and partnership was already established and ongoing. Therefore, the FPLD's prior knowledge and experiences collaborating on a similar project made the FPLD the ideal organisation to run the mentoring programme.

Three further organisations joined the team to provide feedback on documentation, to support peer mentor and family carer participant recruitment and to support dissemination of learning and findings from the project. These organisations were Sibs, Family Fund, and Contact.

Sibs is a UK charity dedicated to supporting siblings of disabled people. Again, Sibs have experience collaborating with the University on other projects, including an intervention evaluation. Sibs were ideally, and uniquely, positioned to recruit adult siblings to the project. Sibs staff also have a lot of experience contributing to project materials and have a wide network of family disability organisations to help us reach our recruitment targets. Sibs have said that:

> *'This has been such an important project for Sibs – having such a commitment to bringing siblings into research has been so refreshing and supportive. Working*

collaboratively with our colleagues across the disability sector has further built relationships, given a real platform for the sharing of ideas and enabled some innovative approaches.'

Clare Kassa, Sibs

The collaboration with **Family Fund** was new. Pre-existing links with Sibs were key to getting Family Fund on board. Sibs recommended the University team to Family Fund and then introduced us – as Sibs' Chief Executive used to work for Family Fund. Family Fund works exclusively with families raising disabled or seriously ill children on low incomes. Family Fund is also unique as a charitable organisation, as they have excellent reach of families experiencing socio-economic deprivation, and they keep good data on the families in their network. At the time of recruitment (but not now), their data made it possible to contact specific groups of families (e.g., families who are from Black, Asian, or minority ethnic communities). This collaboration supported the project aims to recruit families who are experiencing socio-economic deprivation and families who are from Black, Asian, or minority ethnic communities. Family Fund added that:

'We at Family Fund are very pleased to have been able to collaborate with the University of Warwick and the other project partners in progressing what we hope will be a very beneficial research project. By working together and sharing our knowledge, experience, and reach, we have been able to engage many parent carers with this positive opportunity to improve their wellbeing. Our ongoing research programme has highlighted the extent to which parent carer (and indeed whole family) wellbeing has suffered, first as a result of the Covid pandemic and now the cost-of-living crisis. Providing families in need with peer support and access to the online sessions will hopefully provide them with practical tools to help face the challenges ahead.'

Andrew Harper, Family Fund.

The final collaborative partner on this project was **Contact**. The University team had not worked very closely with Contact previously. The pre-existing relationship with FPLD was key to getting Contact on board – as the Director of FPLD had collaborated with Contact before. Contact is a charity for families of disabled children. Contact manages the UK's Parent Carer Forums. Therefore, they have a wide reach to families of people with learning disabilities across the UK. Contact's London groups include a large proportion of people who are from Black, Asian and minority ethnic communities and who are experiencing socio-economic deprivation. Contact said that they:

'…have found working on this project extremely insightful, especially in terms of collaborating on strategies and shared learning around recruiting hard-to-reach groups. In particular, working collaboratively with organisations who support different demographics has been valuable. This will be learning that we implement in future projects too.'

Catherine McGee, Contact

From a University project team perspective, working with the charity partners was a helpful and thoughtful process. The University team were able to gather the partners' feedback on all project documentation and the project processes in a way that improved the project and made it more appropriate for the family carers involved, including supervisors, peer mentors, and family carer participants.

It was highly valuable for the University team to be able to tap into the networks and knowledge base that the charity partners had to support a project such as Mindful Together. Project recruitment of family carers taking part was a thoughtful, and therefore slower-paced, process to explore engagement of family carers who are so often under-represented in research. This has been possible because the collaboration was in place from the earliest stages of the project, and these organisations have been compensated for their time with some direct funding (reflecting the value of their work).

4.2 Recruiting and training peer mentors

One of the strengths of working with charity partners such as Contact, Sibs, and Family Fund was that the charities, particularly Contact, had existing contacts with family carers who were already engaged in similar work (e.g., the Listening Ear helpline run by Contact, which offers one-to-one telephone appointments with a family support adviser for parent carers). The University team and project partners also took a targeted approach by identifying groups who matched the family carer participants we were hoping to recruit, focusing on siblings, and working on strategies to approach brothers and fathers. It was felt that the opportunity to provide meaningful training and paid work for family carers to act as peer mentors would be a valuable opportunity for family carers, and the University team and project partners were keen to reach family carers who may not have had similar opportunities previously.

4.2.1 Application and Interview process

Phase 1 of peer mentor recruitment was much more successful than anticipated, and the FPLD received over 150 emails from family carers expressing interest in the role. As it was not feasible to speak with each of the family carers who had expressed interest, a short expression of interest form to be completed by interested individuals was developed in collaboration with the charity partners. This was then used to shortlist applicants to interview. Following over 150 expressions of interest, 64 family carers completed the expression of interest form and applied for the role. This consisted of 40 parents (no fathers) and 24 siblings (two brothers). The FPLD commented on the high standard of applications, interviewed 15 parents and 9 siblings and appointed 10 parent and 5 sibling mentors.

The FPLD felt that all candidates who were interviewed were appointable, and again noted the high standard and level of enthusiasm from family carers. It was noted that when the expression of interest form was introduced, there were several family carers who did not meet the role criteria as well as would be hoped, and it was felt that this

was likely due to less experience in applying for roles and/or completing forms rather than the individuals not meeting the criteria. However, due to restrictions in capacity, it was not possible to shortlist and interview these applicants. Learning from this process, the University team and project partners have identified that in the future, similar roles may benefit from a more inclusive application process where the role criteria are tabulated, and applicants are explicitly asked to identify how they meet each criterion and to provide examples.

As mentioned, under half of family carers who expressed an interest in the mentor role ended up completing the expression of interest form and applying for the role. The University team and project partners did anticipate that the form would be a barrier for some family carers. Therefore, the University team included a message at the beginning of the form stating: "*If filling in this form isn't accessible to you, but you are interested in the role, please email <named contact> to discuss reasonable adjustments*". However, no family carers contacted the University team about reasonable adjustments. In future work, a low-cost alternative would be to include this wording in the body of the email, rather than the attachments, and perhaps add examples of reasonable adjustments (such as completing the form as an interview with a member of the University team). In future work, we could build in more time for the recruiting project partner to speak directly with interested family carers individually or through group information events rather than relying on response forms.

Anecdotal feedback from the FPLD team also indicated that the high standard of applicants meant that those who were not appointed were disappointed, and in some cases, they reported that they felt that this knocked their confidence. Family carers shared that they appreciated finding a paid role that recognised the value of their caring experience, and so when family carers were then not successful, this was difficult for them. As part of the interview process, the FPLD emailed every applicant with the decision about their application. However, while the FPLD team provided greater feedback upon request for family carers who were interviewed, due to time and practical restrictions, this was not possible for every applicant. In future projects, it may be useful to cost the time needed to provide more detailed feedback to all applicants, in a way that could also be used by family carers moving forward in seeking employment.

In future projects, it would be worth considering how to integrate and formalise skills development throughout the project from the start, so that all family carers, whether appointed or not, have the opportunity to gain experience and/or feedback from the process which may be of use. Another route that could be explored further for those appointed could be whether there would be any Level 1 or 2 certification that may be suitable both for the role itself and future career development.

4.2.2 Training Peer Mentors

As part of the mentoring process, the FPLD identified a previous contact to work as a lead Parent Mentor who aided in the applicant shortlisting and interview process and who ran the peer mentor training in collaboration with the FPLD. Feedback from the project partners identified the need for a lead Sibling Peer Mentor, and one of the newly appointed sibling peer mentors was approached and accepted this role. Peer mentors attended virtual training with the FPLD in June 2022, with 11 of the 15 original mentors attending the two training days as a group. The remaining mentors attended 'catch-up' training later that week, where the FPLD offered training in the evening to enable mentors who had time restrictions to attend. As part of their training and preparation for the role, peer mentors themselves completed the Be Mindful programme.

The training days combined the parent and sibling peer mentors, and whilst this enabled them all to meet and receive training at the same time, it did give rise to some difficulties within the training. These were primarily due to the different experiences of parents and siblings being shared within the training, with some sibling peer mentors sharing stories about growing up with an autistic sibling or a sibling with learning disabilities, and of things that their own parents had done. For example, a parent peer mentor became upset during a training session while siblings were sharing their stories, perhaps due to hearing about these experiences (that were sometimes familiar to them too) from the perspective of a sibling. The University team and project partners reflected on the training process, agreeing that in future work involving groups of both parents and siblings, it would be better to run two separate training sessions, at least initially, to enable both groups to feel more comfortable with their peers and remove any possible tensions between the two groups. It might then be possible to bring the two groups together for a final training session after they have formed their own group identities separately.

It should also be noted that the sharing of personal experiences (as mentioned above) was not a planned element of the training sessions, but that some peer mentors took the opportunity to share their experiences. The University team and project partners agreed, following the training, that it perhaps was not clear enough to peer mentors during the training session what the expectations were about sharing their own personal experiences with other peer mentors. It may also have been unclear whether sharing of experiences with family carers receiving Be Mindful would be expected. Had these boundaries about the training not being a context for sharing personal experiences been clearer from the outset, the experiences of peer mentors becoming upset during the training may have been avoided. Additionally, in cases where this could not have been avoided, pre-planning about how such situations would be dealt with is necessary.

4.2.3 Reflections on the process of peer mentoring

One of the main reflections on the peer mentor recruitment process was to be more aware in future of the numerous commitments that family carers are balancing, which need to be considered not just for the family carer participants, but for the mentors themselves. In total, over the course of the project, five peer mentors (four parents, one sibling) withdrew from their role as a peer mentor. Throughout the project, peer mentors who remained with the project also needed to step back for periods of time to accommodate caring responsibilities and other family circumstances.

Reflections from the project partners and interviews with peer mentors suggested that the way in which this was approached was vital to the experience of peer mentors. Peer mentors shared that often there were feelings of guilt or shame if they were not able to commit to the role at all times, and so there was the need for sensitivity and understanding from those in contact with the peer mentors to recognise that peer mentors were family carers themselves, and this comes with a need for flexibility and recognition of their own responsibilities and circumstances.

The multiple responsibilities of family carers were acknowledged and discussed by the University team and project partners from the start, but future projects may need to build this discussion into the peer mentor training itself to a greater extent, to alleviate pressure on the peer mentors. Also highlighted was the importance of over-recruiting peer mentors, including the flexibility to recruit and train additional peer mentors later in the project being included in the budget. This was done in the current project but remains a key consideration for any future work.

Unfortunately, within this project, none of the five peer mentors who withdrew from their role were still contactable at the time of interviews, and so we were not able to gather more detail about the reasons for their disengagement and barriers to continuing in the role, which would be important to understand further.

4.2.4 Matching Peer Mentors

Peer mentors were matched with family carer participants by the FPLD using a set of criteria which had been previously discussed and agreed on with the wider project team. Most importantly, parent carers were matched with parent mentors and siblings with sibling mentors. In addition, where possible, the age of the person with learning disabilities for whom the family carer cared was matched (i.e., child or adult). Family carer participants provided information on their availability across the week, and the FPLD then matched each family carer with a peer mentor who matched the family carer on availability, carer relationship, and (ideally) the age of the person they cared for.

One of the considerations raised by project partners prior to beginning this process was potentially also matching family carer participants with peer mentors based on gender. However, it was decided that the carer relationship (parent or sibling) was more

important than gender when matching, and we were in any case limited by having no fathers acting as peer mentors and only one brother as a sibling mentor. We did not receive any feedback from family carer participants requesting a mentor matched on gender. In future work it would be valuable to build on the strategies employed in this project and to devise strategies to recruit peer mentors who are fathers and brothers to allow for matching based on gender (depending on family carer preference), as anecdotal feedback from the University team and project partners suggested that fathers in particular may have valued speaking to other fathers in the peer mentor role.

We also received four requests from family carer participants for peer mentors who spoke English as an additional language who would have preferred to work with a peer mentor who spoke their first language. All of our peer mentors mentored in English. However, upon receiving these requests about language matching, the FPLD spoke with peer mentors to ask if anyone spoke additional languages. Some peer mentors did speak additional languages, but these did not correspond with family carer requests. The matching of these family carers was, therefore, carefully considered by the FPLD, and they checked in with peer mentors of family carers who speak English as an additional language more frequently to ensure that they were being supported and progressing with the intervention as might have been expected. In future work, it would be valuable to consider including a translation budget for the project materials and the mentoring materials, as well as specifically recruiting peer mentors who speak additional languages to improve the chances that there may be appropriate matches available. This is particularly important when considering the targeted recruitment of families who may be under-represented in services and research (e.g., Black, Asian and minority ethnic family carers) where an English language-based intervention and mentoring may present a barrier to participation.

4.3 Recruiting family carers to take part in Mindful Together

From the start of the project, one of the aims of Mindful Together was to support recruitment of key groups of family carer participants who were less likely to receive support and were under-represented in the previous research trial (and research more generally). Partner organisations Sibs, Family Fund, FPLD, and Contact successfully worked together on this objective.

The recruitment process was broadly successful, with 76 of the 101 family carers reached through targeted recruitment focused on adult siblings, father and brother support groups, and families in contact with organisations working with those experiencing socio-economic deprivation, and in areas with higher ethnic minority populations compared to the general UK population. For example, in terms of recruiting families experiencing socio-economic deprivation, 61.4% of family carers in the project reported a weekly household income below the UK median, and 25.7% of family carers indicated they were finding it ‘quite’ or ‘very’ difficult to manage financially.

However, there were still challenges in reaching under-represented groups. As part of the project, and following advice from the project partners, the University team contacted over 20 smaller community organisations known to project partners to promote recruitment but with limited success. Family Fund highlighted the importance of existing relationships and building connections with local groups, particularly for groups of family carers who researchers find difficult to recruit.

While Contact's London groups in particular included a relatively large proportion of people from Black, Asian, and minority ethnic communities, and people who are experiencing socio-economic deprivation, it became clear when the University team presented to group leaders that the Mindful Together project may not have been appropriate for many families, as the online mindfulness programme and peer mentoring were both only accessible in English.

The project had very few applications from fathers and brothers who were interested in being a peer mentor and few expressions of interest from fathers and brothers to take part in the Mindful Together project. Anecdotally, our project partners have suggested that this is reflective of other opportunities provided by their organisations. It is not clear why this was the case, but it could be that the recruitment efforts for the project were only reaching fathers and brothers who were already engaged in a support group (as this was a key recruitment strategy), and so we were not reaching fathers and brothers who may not be currently engaged in support groups and may be less inclined to actively seek the opportunities being offered by the project (i.e., to be a peer mentor, and to take part in Mindful Together). It is also possible that the intervention itself was not of interest, broadly, to fathers and brothers, and other approaches or interventions may be more attractive in future work.

4.3.1 Recruiting Siblings

Thanks to the involvement of Sibs, we had great success reaching and recruiting adult siblings both to be peer mentors and take part in Mindful Together. This is one of the biggest successes of this project.

The project designed materials specifically targeted at adult siblings, and the University team presented at sibling meetings online, contacted sibling groups (including a brothers' group), and presented at the Adult Sibling Day organised by Sibs. Given our understanding that brothers may be particularly difficult to recruit both as peer mentors and family carer participants, the team also approached brothers' support groups, both through Sibs and through other family support groups and charities, such as sibling support groups for siblings of people with genetic syndromes. From the wider reflections of the University team and project partners, it is clear that more work needs to be undertaken to understand the needs of brothers in particular when being recruited to and engaging with interventions and research evaluations.

4.4 Family carers taking part in Mindful Together

4.4.1 Views of mindfulness

Throughout the project, the University team recognised that mindfulness, and so the Be Mindful intervention, may not be appropriate for or valued by all family carers. A few family carers who expressed interest did not participate, as they had thought that the intervention would be in person, not online. Additionally, some family carers appeared to want more practical support or support more directly for their family member, rather than the support offered by a self-paced mindfulness intervention for the family carer.

The project partners also suggested that anecdotally, from their wider experience of offering support to family carers post-COVID-19 pandemic, there was a renewed interest from some family carers in creating and engaging with a community, and in receiving face-to-face support. Thus, the offer of an individually delivered, online (albeit with an element of telephone support from a peer mentor) intervention may not have been as attractive to family carers as it may have been pre-pandemic.

Given this understanding that mindfulness and mindfulness interventions may not be wanted by all family carers, it is important in future work to consider where it might 'fit' within the wider opportunities on offer to family carers through project partners and other organisations.

4.4.2 Engagement in the Project Evaluation

The experience and engagement of family carer participants in the project evaluation is also important to consider. There were very low return rates for the short follow-up survey, after family carers received email reminders, telephone calls, and a project newsletter to encourage completion of the follow-up questionnaire. Shortened versions of the follow-up questionnaire were also made available following several reminders. Of the 95 family carers who did not withdraw from the project, 36 completed measures at follow-up: 21 siblings (48.8% return rate) and 15 parents (25.9% return rate). This is a low response rate overall and was also biased towards the family carers who engaged more with Be Mindful and the peer mentoring support.

This experience suggests that gathering ongoing evaluation data for implementation projects focused on evidence-based programmes may be challenging. However, informal feedback from family carer participants suggested that there was some confusion between the Be Mindful automatic reminder emails and those from the University team, meaning that some family carers may have completed follow-up questions and provided feedback within the Be Mindful programme itself, but not responded to the requests from the University team. In addition, family carers did not receive a monetary incentive to complete either the baseline or follow-up questionnaires. Future projects should consider including vouchers for engagement in evaluation, particularly follow-up questionnaires.

Appendix – Academic papers

Murray, C. A., Hayden, N. K., Gordon-Brown, A., Flynn, S., Bonetree, C., Harper, A., Kassa, C., Mahon, D., McGee, C., & Hastings, R. P. (2025). Brief Report: Implementation of online mindfulness with peer mentoring for parent and sibling carers of people with intellectual and developmental disabilities. *Journal of Intellectual Disabilities Research, 1-8.* https://doi.org/10.1111/jir.70057

Gordon-Brown, A., Murray, C., Hayden, N., Hastings, R.P., Mahon, D., & Flynn, S. (2025). "You understand me": Experiences of peer mentors delivering support for a mindfulness intervention to family carers of people with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 38*(4), e70102. https://doi.org/10.1111/jar.70102

Flynn, S., Gordon-Brown, A., Lunsky, Y., Weiss, J., Hayden, N., Murray, C., Burke, C., Howes, S., Mahon, D., & Hastings, R.P. (2026). Family carers of people with intellectual and developmental disabilities' perceptions of the impacts of online mindfulness: A qualitative study. *Mindfulness*. https://doi.org/10.1007/s12671-026-02929-0