



Madrid International Plan of Action on Ageing (MIPAA) Review Submission

Care Alliance Ireland September 2021

Introduction

Care Alliance Ireland are pleased to be invited to make this submission to the Madrid International Plan of Action on Ageing (MIPPAA) Review, being coordinated by the Department of Health. As the Department are aware, the core focus of the work of Care Alliance Ireland is on the support of family carers, across all ages, caring for those across the lifespan. As such, and mindful of the request for information specifically related to the four goals within the Lisbon Ministerial declaration, this submission is structured according to those goals. Two in particular are most relevant to the work of Care Alliance Ireland, and so this submission focuses on these.

Encouraging longer working life and ability to work

We are quite pleased to see specific reference to reconciliation of employment and care work, which we feel is critical to the positive experiences and support of family carers. To this end, with once off support under the Dormant Accounts Funds (carers measure) we have created a new project called Kaleidoscope - Guiding (see Family Carers Back to **Employment** project details https://carealliance.ie/Kaleidoscope). Early impact data from our first cohort of participants (wellbeing, reduced isolation and loneliness) is promising and available on request.

Family carers, largely due to their caring responsibilities, are underrepresented in the labour force. This is particularly true of female family carers. It is a simple truth that for many family carers, their family caring responsibilities will end at some point, although it is difficult to know when that may occur. For others, the caring responsibilities will never fully cease, but can wane and vary throughout the life course. For these family carers, as they age, it can be difficult to return to the workforce having been absent due to the intense family caring responsibilities over months and years. We also know that remaining connected in some way to the









formal labour market is associated with a range of positive outcomes for family carers1.

This online project comprises intensive online courses for family carers not currently in the paid workforce (through both synchronous and asynchronous learning); and meaningful engagement with HR professionals/employers around carers in the workplace.

Working with family carers themselves builds their capacity to re-enter the workforce, both with concrete skills such as cv building and interview skills, and through building self-confidence and personal growth.

By working with HR professionals and employers directly, the project also encourages employers to value the significant experience and skills which a family carer who is ageing brings to the role. Family carers build significant transferable skills such as time-management, organisation, teamwork, communication and empathy. These skills are invaluable across roles and are chiefly developed through experience.

Apart from our work with the Kaleidoscope project, over the last number of years we have also collaborated with other organisations and individuals to maximise the ability of family carers to consolidate work and care. We successfully advocated for the extension of hours to 18.5 per week which a current family carer can work in paid employment without loosing entitlement for payments such as Carers Allowance.

We are collaborators with UCD School of Nursing, Midwifery and Health Systems on the Carewell Project - Promoting Health and Self-Care Among Family Carers in the Workplace (see https://carewellproject.com).

We have made links with other organisations in the space, such as the social enterprise Jobs for Family Carers, who focus of encouraging employers to create and advertise roles that fit in the 18.5-hour eligibility window to enable family carers to apply for more part time roles in different employment sectors.

¹ Attracta Lafferty et al., 'Stage 1 Registered Report: A Scoping Review Protocol to Map the Evidence on Family Carers Who Combine Work with Care', HRB Open Research 2 (23 April 2019): 7, https://doi.org/10.12688/hrbopenres.12905.1.



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Ensuring Ageing with Dignity

Within this section of the Lisbon Declaration, there is one specific point which specifically refers to family carers and those they care for;

promoting the participation of both persons with dementia and/or mental and behavioural disorders and their informal carers in social and community life.

As we are a membership organisation, made up of 95 organisations who work in the community with people with various conditions, all the work that we do works towards this goal. However, with the onset of Covid-19 in 2020, the work of our organisation pivoted significantly into direct supports for family carers for the first time. We set up the Online Family Carer Support Group Ireland, via the Facebook platform in mid-March 2020². It was clear to us that there was a significant need to create a space online whereby family carers could come together to support each other, and to receive accurate information in a timely manner. All in-person supports across ageing, dementia, mental health, education etc. were curtailed, and we found relatively little online supports to take their place, in particular at the beginning of the series of 'lockdowns' which took place throughout 2020 and into 2021.

The project has been very successful, gaining significant membership in a short space of time (currently standing at 2,650, 20.2% of whom are aged 55 and over) Additionally, the group has grown to include 15 volunteers who assist the Care Alliance Ireland team in all aspects of group moderation. These volunteers are drawn from across social work, mental health, dementia supports, counselling and other relevant specialities. Perhaps most importantly, many are former or current family carers themselves who volunteer their time to help the group function as best it can. Having these family carer volunteers is critical to the ongoing success of the group, as peer-peer support has significant benefits for all involved.

Whilst the group is open to all family carers across Ireland, a significant number of our members care for an ageing relative or friend, many with some form of dementia. Others in the group care for relatives with mental health difficulties, often in conjunction with other conditions. Having access to the group, and having the support of the volunteers, staff of Care Alliance, and their family carer peers







https://www.facebook.com/groups/FamilyCarerOnlineSupportGroupIreland/



enables them to receive support and advice, and to take part in social activities such as weekly coffee mornings, online Zoom guizzes, a gardening club, a book club and others. The majority (90%+) of the members of the group had never engaged with a face-to-face carer support group prior to joining the online group.

This is a cohort of family carers who have been enabled and encouraged to create this safe online community around them which they may never have experienced before. Appended to this submission is a summary of feedback received from members of the group (shared with explicit permission from the members). Also appended to this submission is a summary document of the structure of the Online Group, to give more details on the moderation and organisation of the group. The state health services (HSE) have recently agreed to provide ongoing long-term support for this project. This will enable us to continue to deliver innovative and accessible evidence informed interventions for family carers.

Conclusion

The work of Care Alliance is focussed on supporting family carers across the lifespan, caring across the lifespan. In general our work focuses on policy, research and governance, however in the most recent times we have expanded this somewhat with our Kaleidoscope and Online Carer Support Group projects. If more information is required on these or other issues relating to family carers, we are available for discussion and collaboration.





















Background Information on Care Alliance Ireland

There are approximately 500,000 family carers in the Republic of Ireland. Family carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions.

Care Alliance Ireland is the National Network of Voluntary Organisations supporting family carers. Our vision is that the role of family carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life of family carers. We achieve this by supporting our 95+ member organisations in their direct work with family carers through the provision of information, developing research and policy, sharing resources, and instigating opportunities for collaboration.

Our legitimacy derives in part from our membership base which includes a wide range of organisations currently providing services to Ireland's family carers. Our membership is comprised of both large and small, regional and national organisations. We work with organisations in order that they can enhance the information and supports they provide to family carers. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multiagency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We actively encourage collaboration in all our projects. We provide cohesion to those organisations working to support family carers. We commission relevant research that supports quality interventions in the lives of family carers.

By focusing on these functions we enable more of our member's resources to go directly to coal face services.

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Appendix 1: Online Family Carer Support Group Feedback & Engagement Statistics (from members, shared with permission)

"Thank you so much for setting up this group. I've searched for one for years"

"Amazing group. It has helped me in so many ways. I can't thank you enough. It has literally been life changing for me personally."

"Best thing I did for myself when lockdown came. It's my world, I have more in common with so many of ye than I have in my "real" life. It's a great feeling to know that we are all here for each other and ourselves."

"Love this group so much, it has helped me through so much this last year. Thank you for all the lovely friends I have made too, don't know where I would be without you."

"I get great comfort from the group often I don't have to ask a question. It's there."

"Got good advice, support, fun quizzes, clubs, talks, great courses and laughs so thanks for an amazing group."

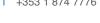
"Many many thanks for creating this support group. I, like many family carers, can feel rather invisible and isolated. I care 24/7 for my beautiful 86-year-old little Mam."

"I'm very happy to be part of this group. It's a great way to be able to say something and people "Get it" without having to explain the situation a gazillion times."

"As a full-time carer to my elderly mother I searched without success for years for some local online support or carers group on the internet and elsewhere. It was hard to believe that there was nothing available online locally in Ireland for us. I was delighted when the group was set up. It is much needed."

"I have only been in this group a while. During this time, although I may not interact publicly due to the people I care for, I find it very beneficial to me as I don't feel alone as a family carer. I read other's stories and can really connect with them. I was even happy to interact with one particular lady as I could help her from my experience. We all help/advise/listen and support each other."

"Being part of the Carers group on line has given me so much support and it is a safe place to bring any concerns, anxieties some where you will not be judged and all questions answered lots of support."





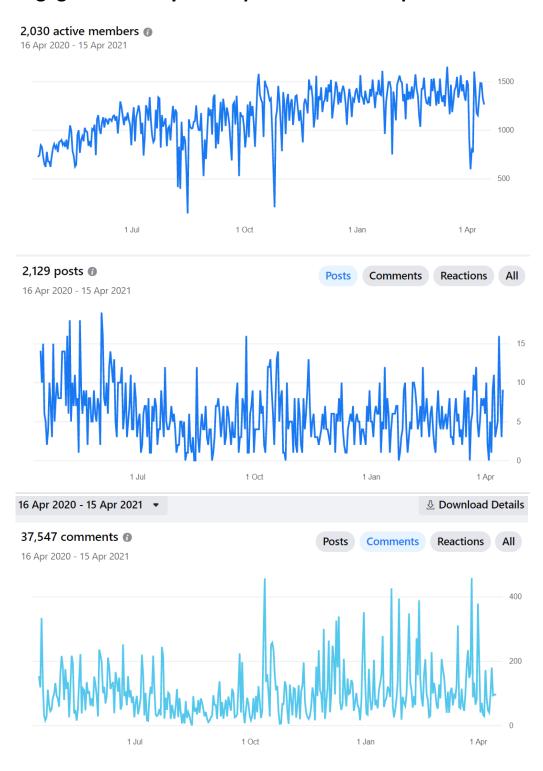








Engagement Analytics - April 16th 2020 to April 15th 2021







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Appendix 2 - Family Carer Online Support Project Operations Flowchart

Family Carer Online Support Project - Operations - July 2021

Group Link URL

https://www.facebook.com/groups/FamilyCarerOnlineSup portGroupIreland

Video Explaining How to Join Facebook and Join the Group

https://youtu.be/teNo7TwDbJ0
Promotional Video https://youtu.be/Hvr-TbFoDHQ

Members of Group (c2,562 >95% active)

Feedback/Efficacy

- Extensive Positive Qual. Feedback 94% Member Retention/12mths
- Key Impacts/Processes Emerging Peer Support-Possible Improvement QOL/Anxiety/Isolation
- Long Term Efficacy/Meaning Uni. of Limerick PhD- Began Oct 2020



Recruitment/Application Process

Inclusion/Participation Criteria

- Must have/be willing to use Facebook (Through 'Private Group')
- Live in the Rep. of Ireland & aged 18+
- Provide Unpaid Care to Family/Friend/Neighbour
- Agree to Rules of Group

(NB - Respect Privacy of Caree)

Participant Recruitment (Family Carers)

- 95 NGO Member Orgs of Care All./ Other Contacts
- Word of Mouth (Increasingly Important)

Application Process

Apply to join the Group (Private Group) through Facebook - Answer 3 screening questions (per Inclusion Criteria above)

Application Considered by CAI Staff. Approved or

(If questions not fully answered - Applicant Private Messaged – Asking to resubmit request to join)

Contact Details

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Objectives - Mitigate impact of loss of services to family carers and cared for due to Covid-10 - Contain Anxiety - Reduce Isolation -**Use Power of Peer Support**

Activities Within the Group

Posting Messages (Core Activity) c 6 p/d

- Comments/Discussion (c 109 per day, c288 reactions) -Anon, posts facilitated NB/ GDPR
- Peer support 'I am not alone'
 Information- Dilemmas Top Tips- Positivity Posts Cooking Posts - Pinned Posts/Threads: Remembrance/

Petitions/Research/Humorous 1-2-1 Input/Casework Core Activity c125 clients

- PM's/Phone calls/E-mails variable levels of engagement
- Refer to Carer Support Orgs/SW Mental Health Services

Educative Inputs Video pre-records - 'Subject matter Expert' - Live Q&A's

Zoom Quizzes Monthly - Informal/Fun Book Club Bi-monthly -Distribute Books – Break Out Rooms Distribute Books (c550) Irish Red Cross 'Helping You Care' and Condition Specific books/resources

Weekly Online Drop In

Informal Competitions Regular Books/Gifts/Care Packages Gardening Club - Chair Yoga - Coffee Mornings

Reflections - Iterative - Volunteer Strength Moderation - NB Peer Support - Evolution of Group Purpose - A very social Social Media – Other NGO's responses? – Risks of GDPR Breaches – Project will be needed post Covid19

Resourcing

Volunteer Supporters (17) (1 p/t Staff Member)

- Current and Former Family Carers (9)
- Health and Social Care Professionals (10)
- Including 5 Professionally Qualified Social Workers
- Other Backgrounds (Researchers/Post Graduate Psych. Students) (4) (Some identify in more than one group.)
- 7 day and On-call rota

Roles of Staff/Volunteers

- Screen Membership Applications
- Informational Documents Uploaded Within Group
- Approve/Reject Suggested Posts (Tone/GDPR/Off Topic?/Adding Value?)
- Welcome New Members
- Monitor/Moderate Posts/Comments
- Communicate/Reiterate/Demonstrate Values
- Share Other NGO's/Organisations Relevant Posts
- Consider New Activities
- UK 'Mods Bods' FB Group- Best Practice Online/Forum Moderation
- Referrals/ Safeguarding Sustainability/Finances

 $\textbf{Safeguarding} \,\, \textbf{Consult Team - PM's/Phone Call/Zoom to Family}$ Carer - Consult Local Mental Health Service - Contact Gardai

Engagement Data (12 mths.) - 2.015 posts - 39.609 comments – 104,927 reactions – 1 complaint – 100's of positive comments and qualitative feedback

Private FB Online 'Mods/Vols' Group

- Peer Support -Bi-Weekly Zoom Meeting
- Discuss Practice Issues/Dilemmas
- Discuss Group Posts/Tone/Engagement
 Information/Policy Updates



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