

Background to Intervention

Family carers are proven to be at a greater risk of isolation, loneliness and depression than the general public^[1]

March 2020 – this initiative emerged following Covid-19 lockdown and pausing of in- person supports to family carers

- Sudden shutting of services and supports for family carers'
- Our organisation pivoted overnight. Staff led initiative with board and funder support.
 - Social work informed approach. Extensive staff experience in online group moderation in their private lives.
 - Set Up a Closed/Private Facebook group format.
 - Key early and ongoing role of volunteer family carers and health and social care professionals.

1 Aims / Purpose of Intervention

- Facilitate the sharing of reliable, trustworthy information
- Facilitate peer support between family carers
- Signpost to services & other organisations
- Provide a safe virtual space for family carers to seek reassurance, ask questions, receive peer support and contain raised anxiety
- Help family carers feel less alone, less isolated, more supported and more valued
- There's also an element of socialising and fun in the group

2 Theoretical Underpinnings

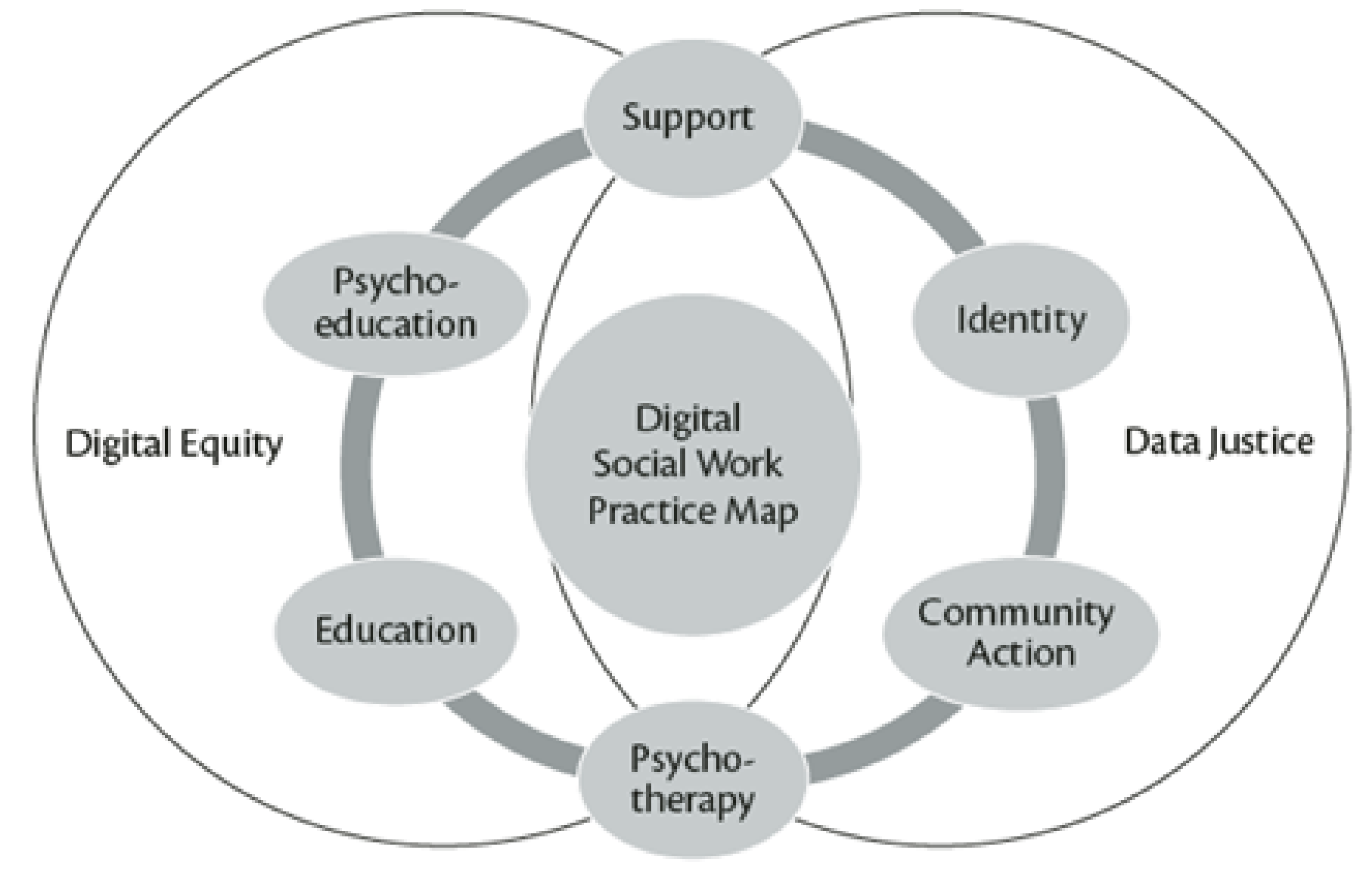
- Social Support Theory**^[2] – (emotional, informational and instrumental). 'You are not alone'; social activities for the carer
- Reciprocity Theory**^[3] – posting question/dilemma, posting suggestions, private messaging
- Communities of Practice**^[4] – separate moderators and volunteers group, ongoing training, individual support for volunteers
- Social Comparison Theory**^[5] – advantages and disadvantages

3 Problems this Intervention Addresses

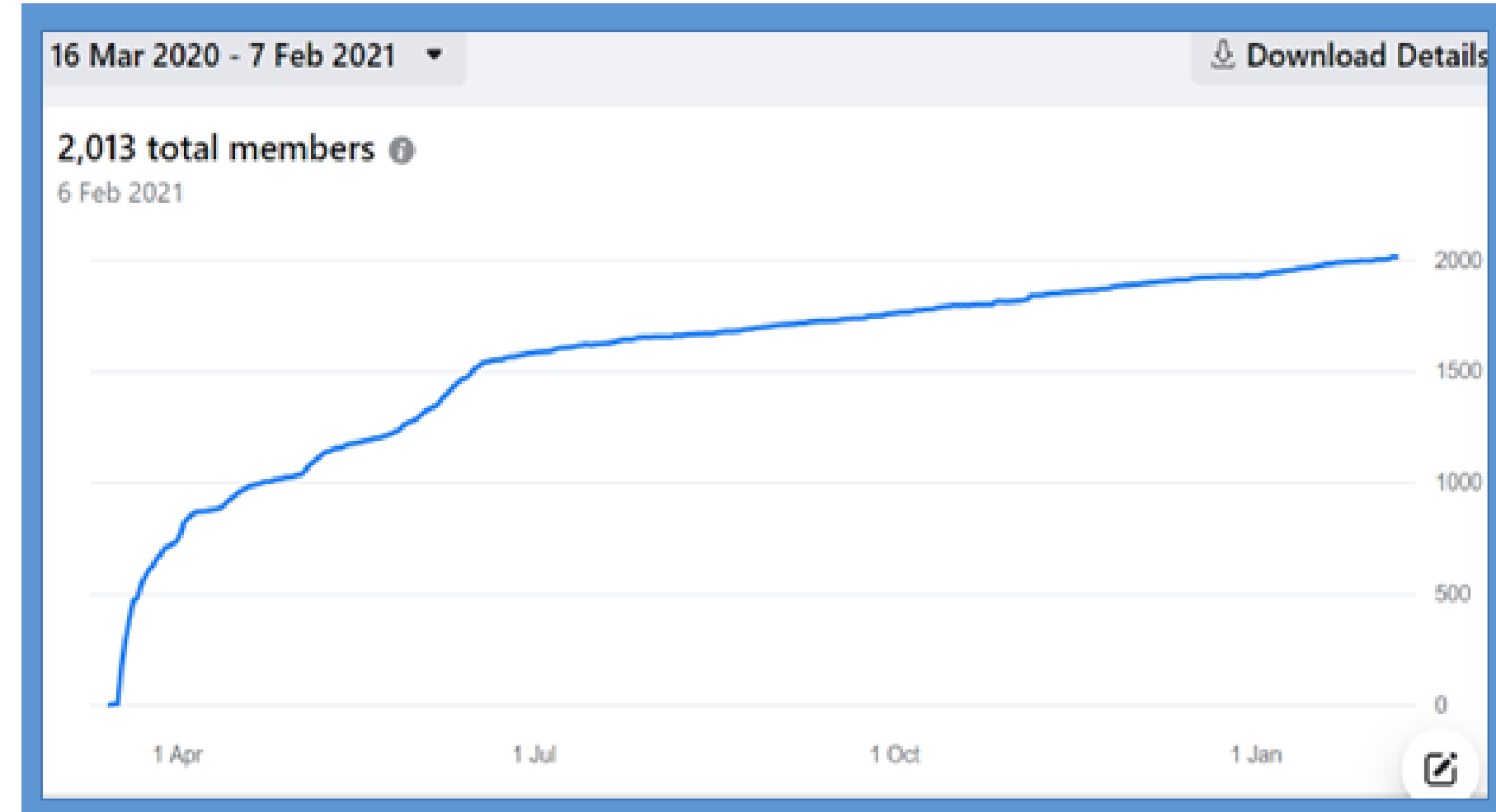
- Problem 1**
Traditional public in person support groups require considerable time investment by client, travel time and have privacy issues
- Solution 1**
Accessible at-home to >95% family carer population, need high speed internet.
- Problem 2**
Lengthy waiting lists
- Solution 2**
Online project has no waiting lists
- Problem 3**
High cost of 1-2-1 interventions
- Solution 3**
Intervention cost <€20 per client (no cost to participants)

Facebook Group Link

Project Website Page

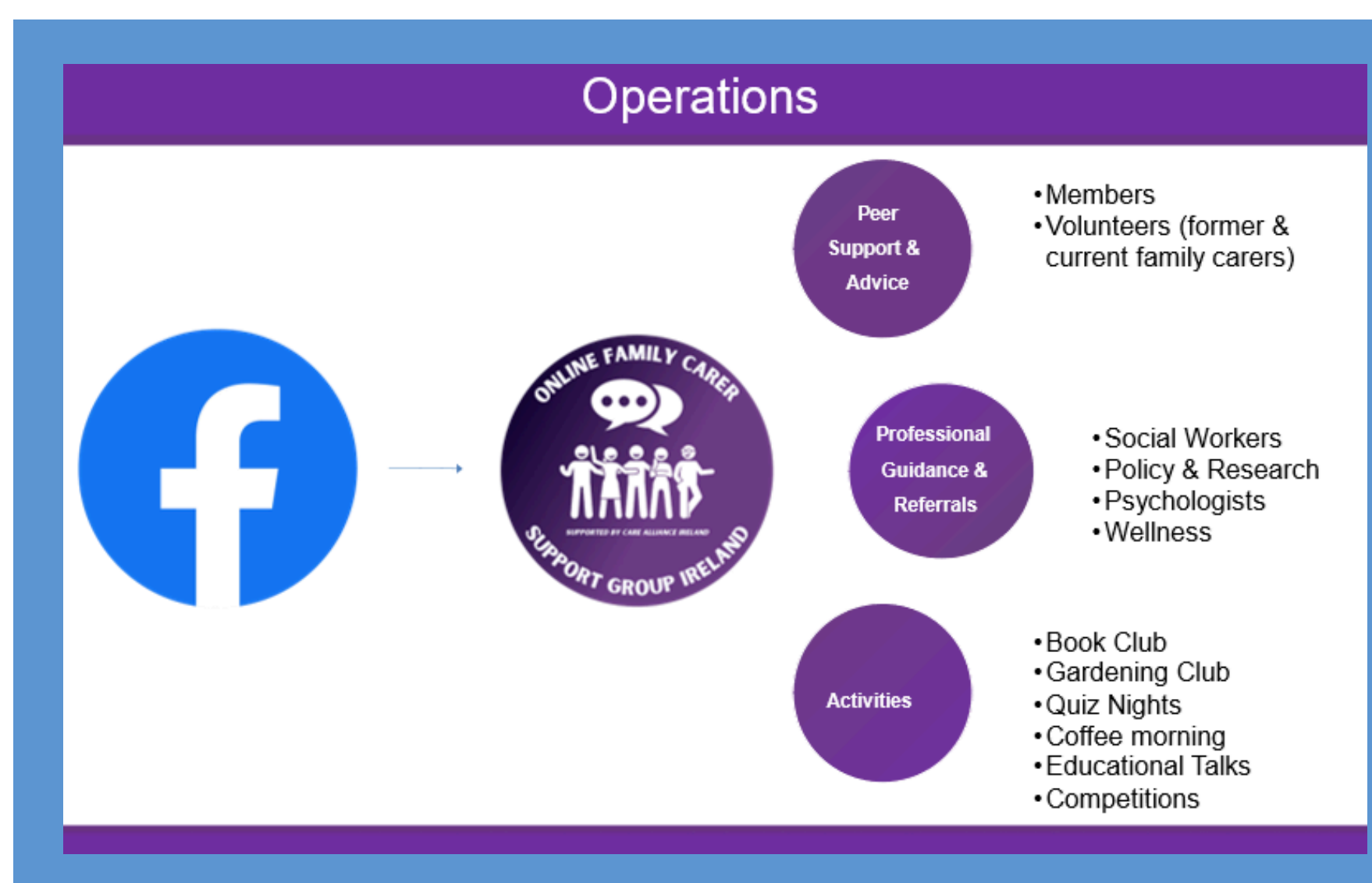


Membership Growth Over First 12 Months



Operations

5 Current Project Status



- November 2024:** 4.5 years in operation. Membership is approaching 9,000. Client Engagement (>80% over 60 days) and Retention (97%, year on year) remain very high.
- €175k annual state funding secured (from the Health Services Executive, as part of The Carers Guarantee).
- Research collaboration continuing with University of Limerick and Indiana University.

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)

6 Culture

- Zero tolerance for nastiness – especially to other members and to volunteers
- Ambitious, Innovate and Iterative
- High-quality, considered moderation
- Ongoing staff and volunteer training and continuing professional development (CPD)

7 Novel Aspects of Intervention

- Regular care packages and other gifts to family carers.
- Annual family carer participation in creating calendar
- Modest financial re-imburements for Volunteers (ICT equipment, contribution towards internet fees)

8 Expansion of Associated Activities



10 Moderation Styles and Dilemmas

- To what degree should we facilitate 'venting' of problems and challenges?
- Is a members post relevant to the wider group?
- Can members identify individual organisations, services?
- How do we manage the repetition of questions?

Reflections

11 Operational Challenges

- Facebook Platform not to everyone's liking (but it's where people are)
- Ongoing caution about storage and use of data (protocols, delete data regularly)
- 24/7 nature of online platforms (boundaries, staff support, rotas)
- Few publications detailing efficacy (Coulson, Neil et al – focus largely to date on self-management of health conditions)^[9]
- Consistency in moderation (culture of the group; protocols developed; frequent team/volunteer meetings)
- Risk of vicarious trauma (training, self awareness)

12 Growing Evidence Base

More research to come (Ref; PhD. Rosemary Daynes Kearney – three research Questions)

- Why are they important?
- What works well?
- Who uses them?

13 Emerging Research Themes

- The Power of peer support - being part of a 'tribe'
- The group are a Tribe and the Tribe 'gets it'
- The Tribe is a lifeline and life-changing
- The leadership of group moderators helped create the Tribe identity^[13]

14 Group Member Feedback

"Bravo to the staff, & all the volunteers! What an amazing group ye [sic] have created & what a wonderful support, comfort & safe place it is for all & any of us. Knowing it's here, is huge, no matter how alone or physically isolated you are in your caring role, here there is always a kind word, sage advice & camaraderie, such a gift..."

"I would just like to say Thank You as since I have found you, I have had a beautiful experience in speaking with the kindest and caring people, people who know and understand like myself the work anxiety stress and sometimes heartbreak that being a family carer can be. Thank you so much"

"Thank you to the whole team for everything you guys do, you go way above and beyond what is expected of you. I don't post often or interact as much as I would like, but just reading everyone's posts and knowing the activities are there for when I can do them is a major lifeline for me. Xx"

Published Research Papers:

Scoping Review^[10]

Social Identity and Online Support Groups^[11]

Media Article^[12]

15 Challenges and Tips

- Find where your target group is and go there – Facebook, proprietary boards; pros & cons
- Facebook has issues re: privacy & security. Must balance risk vs reward as no intervention is without risk.
- Significant work in early stages to set up; weekends and evening rotas are key
- Use moderation tools if you have them e.g. for example anonymous posting
- You will make mistakes – learn and develop new strategies for them
- Efficacy – bring on board early on (evaluator, PhD/Third Level)

Long-term Collaboration with School of Social Work, Indiana University (Dr. David. Wilkerson)

16 Outcomes/Results/ Client Data

- Reaching new underserved family carers - 91% report never having engaged with face-to-face support group. This suggests that even before Covid-19 hit, many family carers were isolated and underserved by traditional support group models.
- Being a member of our online support group does have a positive impact on our members^[14]
- 93% of members found the group helpful to their own situation
- 97% had never experienced nor witnessed any negative experiences in the group

