

# **A whole-system recovery programme for families of people with mental illness - evaluating its impact on family members' caregiving experience**

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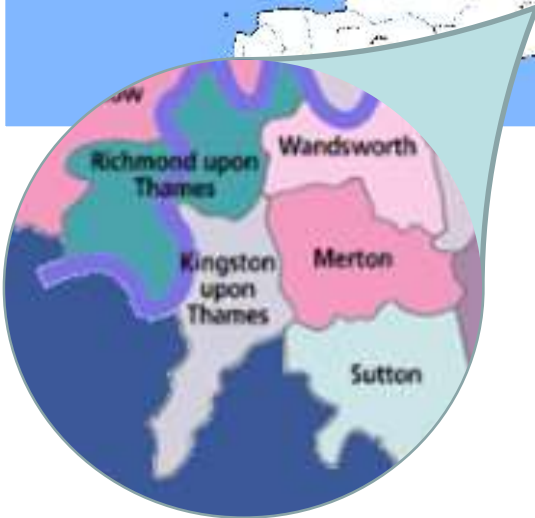
# Aim of Presentation

- To describe a structured recovery programme for families living in South London.
- To report the evaluation of the impact of the programme on family members' caregiving experiences.
- To consider ways to promote peer support and family inclusion through the evaluation and development of the programme.

# South West London and St George's Mental Health NHS Trust



- 20,000 people are receiving treatment and care
- Operate from 90 sites with 3 inpatient sites & approximately 430 beds
- Community Mental Health Teams as well as outreach, crisis and home treatment services
- Trust employs 2,000 staff and has an annual budget of £160 million



# CARERS MATTER

The shift in mental health policies away from hospital-based care **makes family caregivers essential in helping people with severe mental health problems** to live in the community, but the role is often challenging **and has a huge impact on the caregiver's own life.**

Family caregivers have typically cared for their loved one for

**15** years.

Caring can also involve **positive experiences**

with more than

**half** of

caregivers discovering **inner strength.**



More than **1 in 3** family caregivers are at the **point of reaching breaking point.**

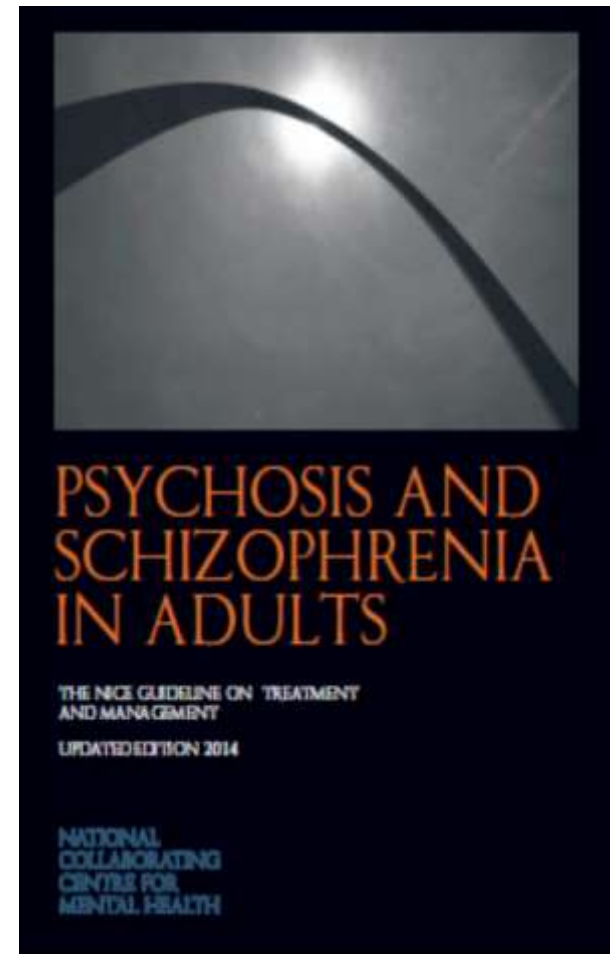
**4 in 10** feels **unable to cope** with the **constant anxiety** of caring and experience these feelings "quite a lot" or "sometimes"

## 1. THE HIGHS AND LOWS OF CARING

**Family caregiving** for people with severe mental illness **involves feelings of stigma and burden,** however, these experiences can be coupled with **positive caregiving experiences.**

# Theory, Practice, Provision Gap

- NICE (2002, 2009, 2014) – FI recommendations
- Lived experience conveys varying levels and extents of implementation as well as adaption of models in service provision (Berry & Haddock, 2008)
- Clinical intervention and research needs to address the evolving evidence base as well as the recovery philosophy (Askey, Gamble & Gray, 2007)
- 2015 EUFAMI Caring for carers survey (C4C) highlights huge gaps in recognition and support





## 2. THE REAL-LIFE CARER

The **typical family caregiver** for a person with severe mental illness is **female (80%)** and **around 60 years old**, with

- **76%** taking care of a son or daughter
- **7%** for a brother or sister



- **10%** for a partner or spouse
- spending an average of **22 hours** each week caregiving

The job of caring is **often solitary** and **with little respite**

- Nearly half (**47%**) never take a break from caring
- **36%** of carers are the only caregiver

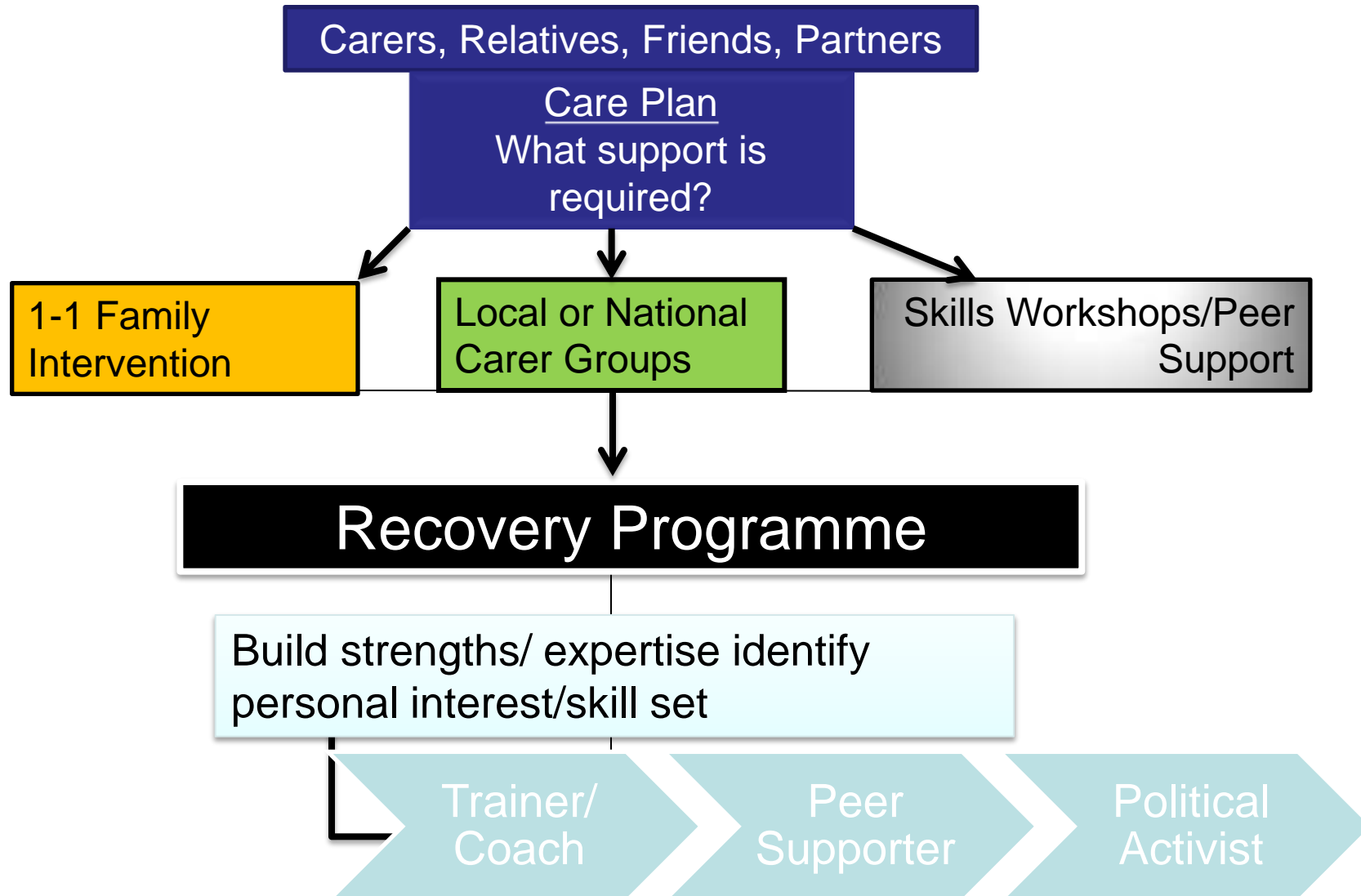


- Only **6-8%** rely on paid respite care
- **36%** rely on friends and family

# Family members go through different recovery stages

- Members can support one another but they can't recover for one another
- Emotional reactions are natural and do not imply there is something wrong
- Roll with phases of self discovery, renewal and growth
- Need different support and different skills during the journey
- Different support models are required

# Development Programme





# Inpatient Skills Workshops

- **share skills and information at time of crisis**
- **facilitate sharing of experiences and process the emotional upset**
- **pool solutions for common problems and encourage trying new coping mechanisms**
- **expand problem-solving capacity**
- **provide a network to combat isolation and stigma**
- **engage with services**
- **space for specific issues or carers' interests**



- **Promote inclusion on acute inpatient wards**
- **Identify family members and friends who could support others during similar experiences**

# SWLStG's Workshops

Sessions	Topic and Content
One	<b>Understanding psychosis and the importance of friends and family in recovery</b> Shares information and knowledge of psychosis and discusses how families and friends roles can be valued
Two	<b>Dealing with crisis and getting through the mental health system maze</b> Explores personal experiences of crisis and examines strategies used to overcome these
Three	<b>Enhancing Communication</b> Shares specific skills, as effective communication can help to express concerns and pre-empt stress
Four	<b>Problems in caring and how to tackle them</b> Considers and examines the rationale for using problem solving
Five	<b>Maintaining Wellbeing and Recovery</b> Reviews how early warning signs, management steps and coping strategies can be amalgamated into a simple, collaborative wellbeing plan

# Experience of Care Giving Inventory (ECI, Szmukler et al, 1996)

<b>Category</b>	<b>Sample statements</b>
<b>Difficult behaviour</b>	Moody, irritable, ...
<b>Negative symptoms</b>	Withdrawn, uncommunicative,
<b>Stigma</b>	Covering up his illness, ...
<b>Problems w services</b>	Dealing with psychiatrists, ...
<b>Effects on family</b>	How he gets on with other family members
<b>Need to backup</b>	Having to support him, ...
<b>Dependency</b>	Unable to do things you want
<b>Loss</b>	What sort of life he might have had
<b>Positive personal experiences</b>	I become closer to friends
<b>Goods aspects of relationship</b>	He's good company

# Skills Workshop Pilot Results

- 10 respondents attended all 5 sessions and completed a ECI and a workshop evaluation form:
- 1 female partner; 4 Mothers; 2 Fathers; 1 Brother, 1 Male Friend/Service user; 1 other
- 3 others completed a standalone workshop evaluation form
- 13 participants caring experience ranged from 2-15 years
- All using secondary services (ranged from CMHT, early intervention – acute admission)



# Qualitative Feedback

*“good informal support, understanding, supportive group”*

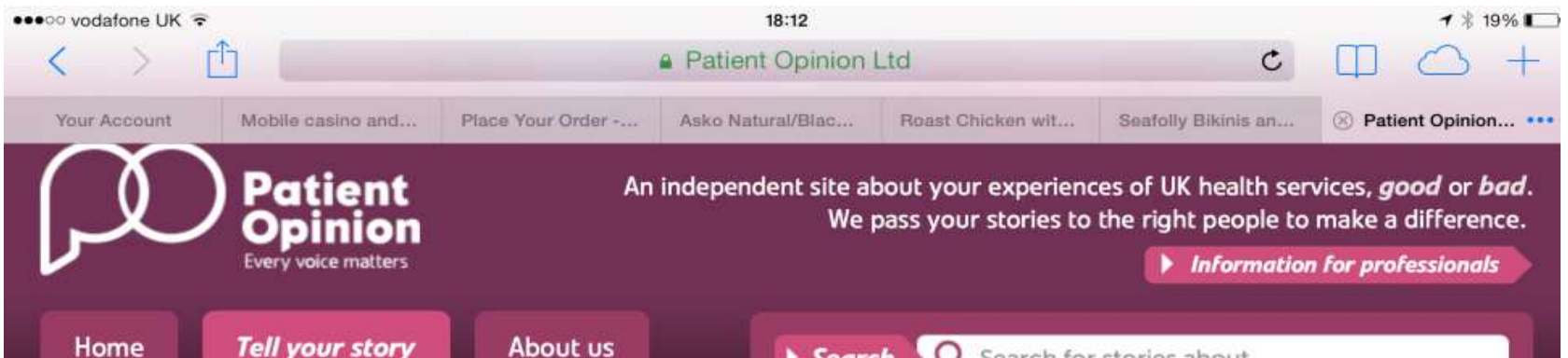
*“been useful having a framework, so the group does not become a sound-off”*

*“at last, someone cares about us”*

*“Husband friendly”*

- *The workshops were very useful and certainly opened doors and avenues, on how to equip oneself in taking different strategies and approach angles in terms of communicating with my son....*
- *It was helpful that the facilitators were trustworthy, they seem to feel safe and relaxed talking about issues of concern.*
- *Very useful tips, we discussed the tool box I use and how I protect and look after me when caring for my loved one.*

# Qualitative Feedback



eg Leeds General Infirmary, heart surgery, depression, SS OEN

## "Recovery College, friends + families skills workshop"

About: South West London And St George's Mental Health NHS Trust / Adult mental health

Posted by [Gates61](#) (as the patient), 2 months ago

Caring for loved and suffering from a psychosis is a traumatic and daunting experience. These workshops equip family and friends with some of the skills and knowledge to cope and aid the recovery process. This is especially important in the field of mental health care which has had and continues to have major funding cuts. Well done to the recovery college for providing these vital workshops.

More about [mental health and psychosis](#)

### STORY HAS A RESPONSE

This story has had a response

### Story summary

What's good?	What could be improved?
<ul style="list-style-type: none"><li>recovery</li><li>skills</li><li>workshop</li></ul>	

### Activity

18:18

## "We shouldn't have to fall upon gems like this"

About: South West London And St George's Mental Health NHS Trust / Child and adolescent mental health

Posted by [NHSlover](#) (as a relative), 5 months ago

This is a quick but huge thank you to super nurse Catherine.

My daughter and I recently went to her evening skills workshops for family and friends. She made us feel so normal. She made us laugh (the first time in at least a year that I can remember doing so) was so welcoming and took such a personal interest in us, we warmed to her immediately.

Her communication session has made me more confident in speaking to my daughter about what she has gone through. Without Catherine and the way she runs these sessions I don't think me and my family would be where we are.

We shouldn't have to just fall upon gems like this - the NHS must provide these sessions everywhere - in this way families wouldn't have to struggle through the bewildering maze of mental health services! |

More about [mental health](#)

### STORY HAS A RESPONSE

This story has had a response

### Story summary

What's good?	What could be improved?
<ul style="list-style-type: none"><li>communication</li><li>Family involvement</li><li>service provision</li><li>treatment</li></ul>	<ul style="list-style-type: none"><li>More sessions</li></ul>

**Initial feelings:** *confident and thank you*

See which organisations have read this story

**20** staff members have read this story

- 15 at South West London and St George's Mental Health NHS Trust
- 3 at London Borough of Southwark
- 1 at Stones End Day Centre



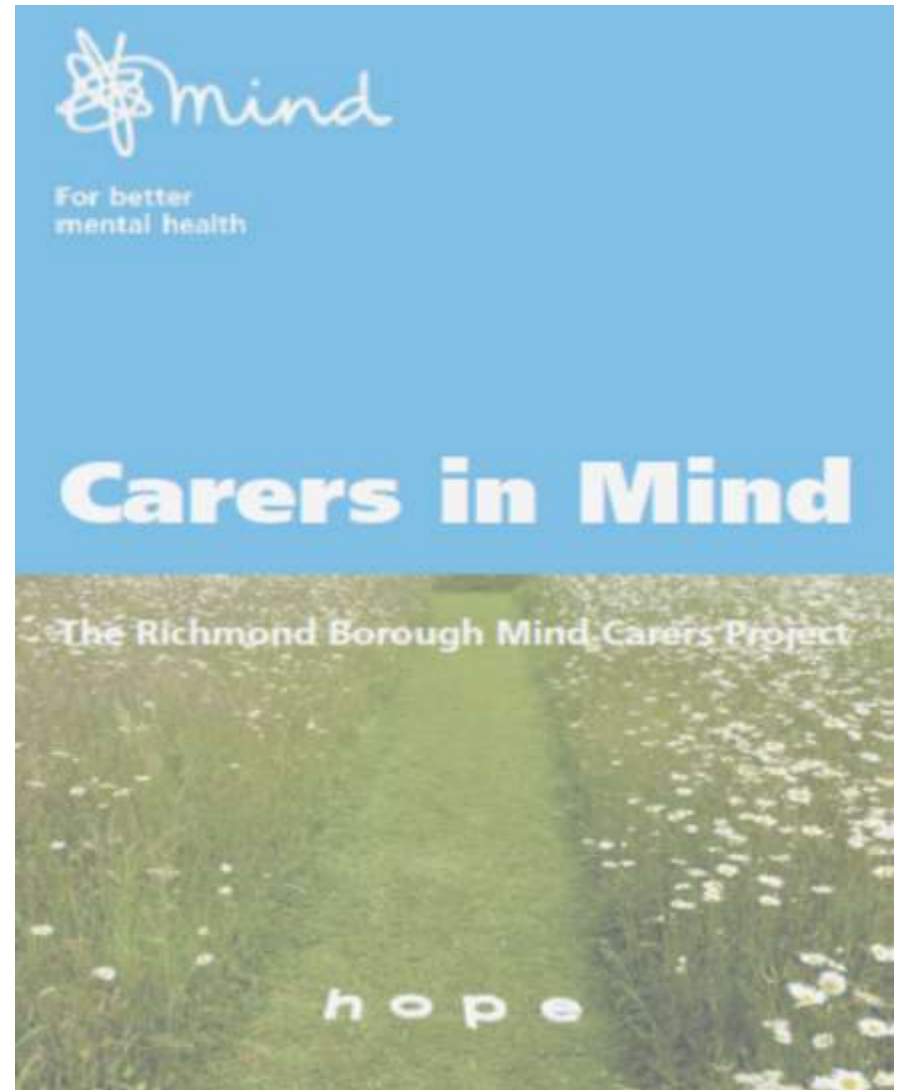
# ECI sub-category item

## Problems with Services

Category & Inventory Item	Pre-group score	Post-group score
How health professionals don't take you seriously	M=2.7 SD=0.7	M=1.5 SD=0.5
Difficulty getting information about illness	M=2.8 SD=0.2	M=2.0 SD=0.2
How to deal with mental health professionals	M=2.3, SD=0.9	M=1.8, SD=0.8
How health professionals do not understand your situation	M=2.3 SD=0.9	M=1.8, SD=0.25
Dealing with psychiatrists		
How to complain about his care		
Finding out how hospitals or mental health services work		
Doctor's knowledge of services available		

# Working in Partnership

- Families with self-directed skills is an integral way to encourage recovery changes within the person they care for (Rethink Mental Illness 2006)
- Family members can promote wellbeing, self-management and service engagement (Kling et al 2008)
- Would a longer coproduced, co-facilitated programme have more impact?



# 10 Week Recovery Programme

Week	Aim of Session	Recovery Programme Content
1	Personal understanding and exploration of experiences	Personal recovery and differing relationships Recovery Word Game Telling our stories, recovering our lives
2	Knowledge and Information sharing	Understanding mental disorders and difficult behaviour symptoms
3		Medications, side effects, strategies for medication adherence Current research related to the biology of brain disorders and evidence-based treatments
4	Personal understanding and exploration of experiences	Hope – an agent of change Sharing personal experiences of devastation and recovery Gaining empathy lived experience of mental illness
5	Self awareness development	Change theories Introduction to coaching Problems into goals Validating Strengths
6-7	Skills Development	Communication skills (part 1&2)
8		Advance directives, crisis plans and relapse prevention
9	Resources, knowledge and information sharing	What is out there? Peer support opportunities and social inclusion
10	Review & Evaluation	Skills booster, where we go from here, follow up session dates

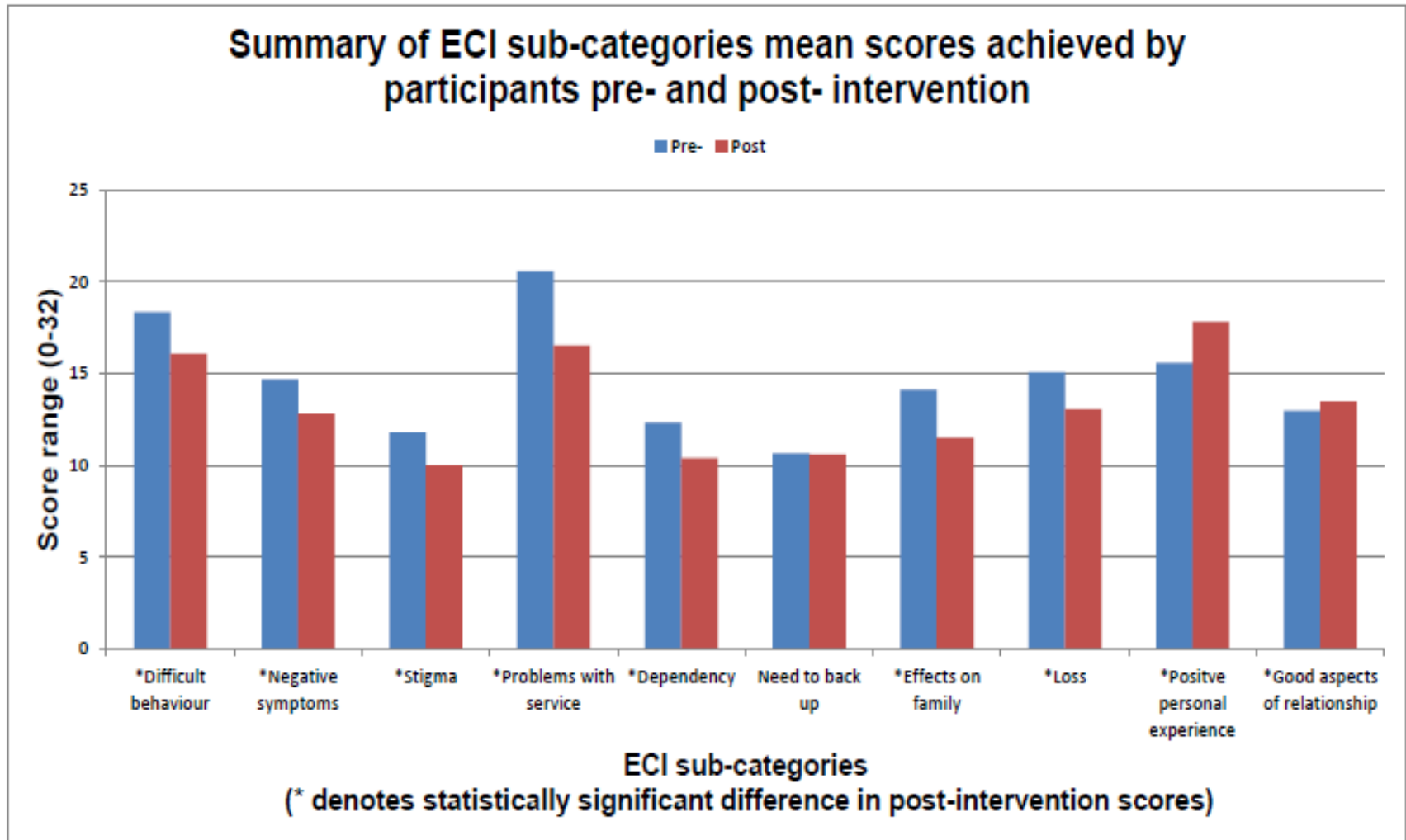
# Participants and Relationship to Service Users

- 3 hour evening recovery programme
- Three cohorts
- Group size average 10 people
- A volunteer sample of family members completed before and after Experience of Care Giving inventory
- Total = 25 completed ECI
- 1 Daughter, 4 Fathers, 14 Mothers, 2 Brothers, 4 Sisters
- Mean age = 53.3 (SD = 10.6) years
- Mean length of time caring = 9.53 (SD = 8.5) years

# Experience of Care Giving Inventory (ECI, Szmukler et al, 1996)

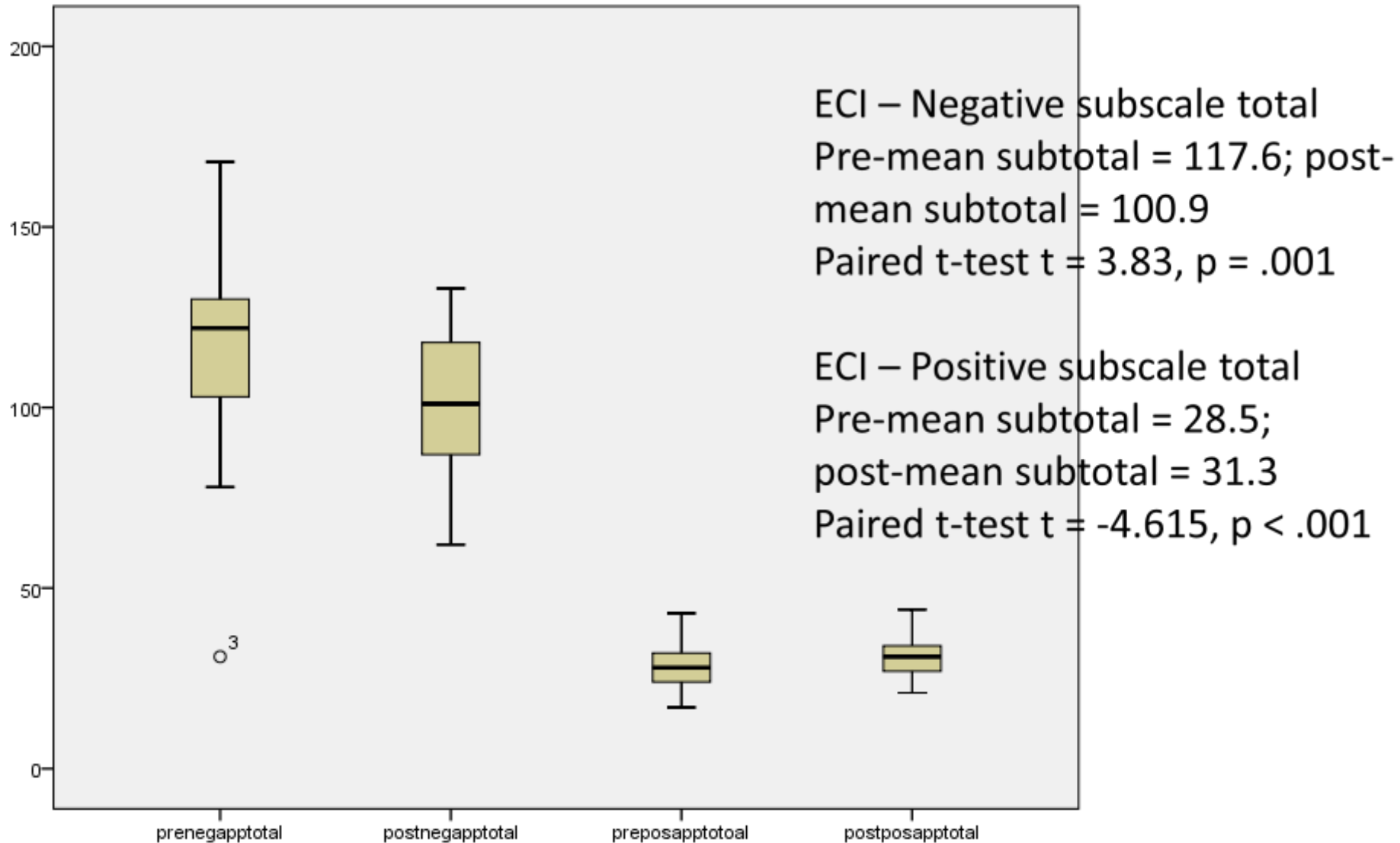
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# Matched paired t-test (2-tailed) on various ECI sub-categories identified improvement





Box plots illustrating the ECI-negative and positive appraisal totals at pre- and post- time points.



# Qualitative Feedback

**“Without these sessions I don't think me & my family would be where we are now”** Mother, cohort 3

***“Its not just about coping, but learning how to cope well!”***

Sister cohort 1

# Qualitative Feedback

*"I seem to have made myself more approachable, more trustworthy, and more brother-like again.*

*A confidante and an ally. As it used to be.*

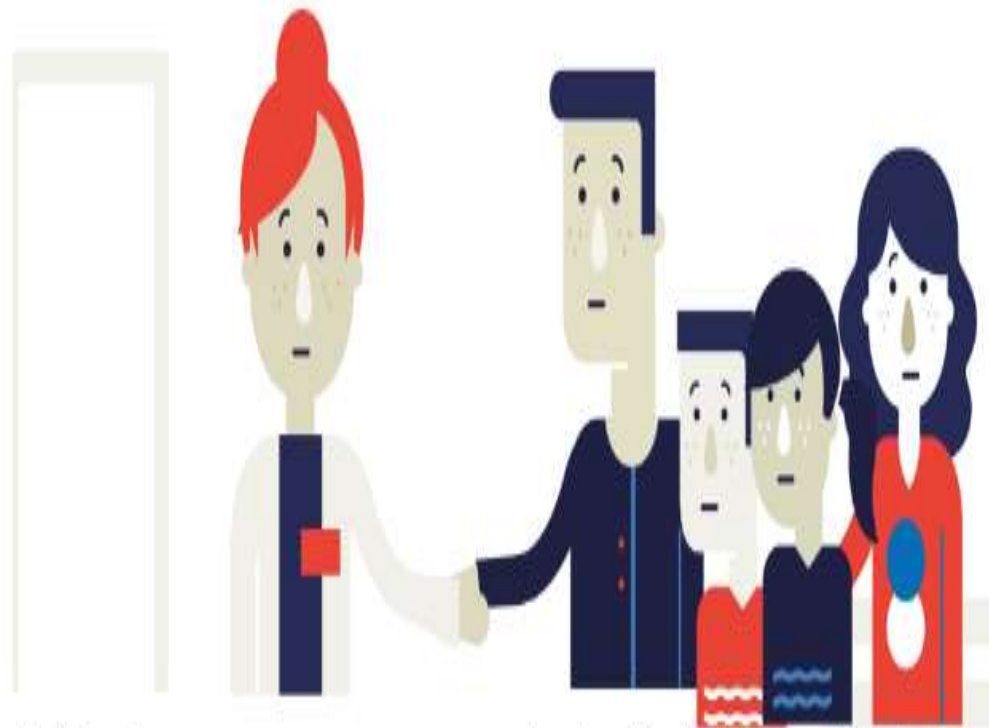
*Getting that back again after all these years is more than I can manage to express. It's utterly invaluable, to us both. I reason that this is partly to do with regaining a sense of confidence again - something that comes from knowing the right thing to do"*

Brother, Cohort 2

# Recommendations

- Engagement process – ask, ask, ask again
- Build recovery programme content on ECI outcomes & narratives
- Evaluate participants development post recovery programme
- Carers' involvement in leading groups and service development
- Review provision and continue to promote inclusion ...

Around 9 in 10 want more opportunities to meet and share knowledge and experiences with:



Professional carers  
**93%**

As well as with other family members and  
informal carers  
**90%**

# Introduce 3iS

- **3iS** - a protocol to ensure that all carers, families and friends accessing services are:
  - Identified
  - Informed
  - Involved
  - Supported.....in ways that meet their needs and the needs of people using our services



# CARERS, FAMILIES, AND FRIENDS

**MENTAL HEALTH SERVICES THROUGH THE EYES OF A CARER...**

- Involved in planning programme
- My partner is working on recovery
- Diagnosis
- Symptoms
- Engagement
- Medication
- Future plan

**LEARNING:**

- RECOVERY BUT NOT LONG
- NORMALLY RECURSIVE
- EFFECTIVE SUPPORT IS AS GOOD AS DRUGS
- Engagement of carers
- THERES LOADS OF SUPPORT OUT THERE

**KEY FACTS**

- ASK OPEN
- ASK SERVICE USER
- ASK GP
- ASK FAMILY
- ASK AT CRISIS

**IDENTIFYING CAREERS**

- ASK OPEN
- ASK SERVICE USER
- ASK GP
- ASK FAMILY
- ASK AT CRISIS

**MATTER**

- EMPATHY
- KNOWLEDGE
- LISTENING SKILLS
- INITIATIVE
- CARING VALUE OF ROLE OF CARER

**QUALITIES**

- Active
- Positive
- Family
- Recognising my needs as a carer
- Non judgemental
- Sensitivity
- Empathy
- Perseverance
- Empathy
- Sensitivity

**INFORMATION & SUPPORT**

- Advertising
- Resources
- Support groups
- Available out of office hours
- Networking

**RECOVERY COLLEGE**

- Building schemes
- Self help groups for carers
- Working with the arts and using living cases
- Communication skills
- Coping in a crisis
- Recall in reading
- Medication
- Where to get help

**RETHINK MENTAL ILLNESS**

- Recovery
- Support
- Recovery
- Recovery
- Recovery

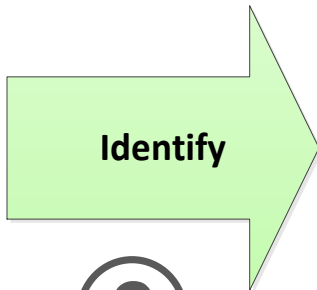
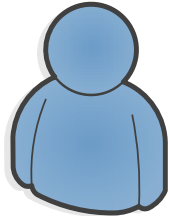
**IMPORTANCE OF SIBLINGS**

- NICE positive
- Developing narratives



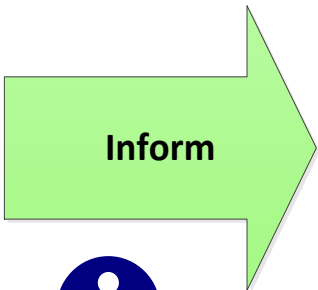


# Carers, Friends and Family (CFF) 3iS Protocol: Identify, Inform, Involve and Support v1.0



Ask early and often  
Ask the service user  
Ask widely  
Ask for advice  
Ask at crisis, transition, review points

Think Family  
Be interested  
Identify one main CFF  
Set up a carer's record



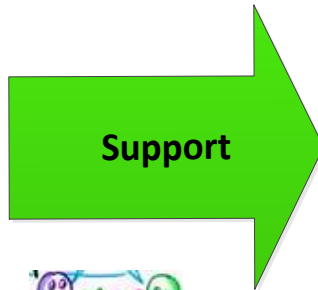
Provide information early & on-going  
Relevant, understandable, meaningful  
Information in suitable formats  
Volume and detail appropriate  
Support options information

Information should be:  
Responsive  
Repeated  
Personalised



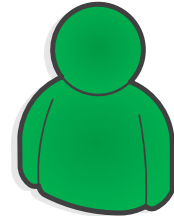
Agree who will be involved  
Offer joint appointment (service user/CFF)  
Invite CFF to key meetings  
Ensure legal requirements are met

If CFF can't be involved for legal reasons at any point – explain why  
Lack of decision specific capacity?  
Employ Best Interest Decision and involve family where possible



Offer meeting to CFF early  
Consider a joint meeting  
Help CFF identify sources of support  
Info must meet the needs of the CFF  
Offer psycho-social interventions

Be clear and kind  
Honesty about boundaries  
Be alert to any risks to CFF  
Use a broad Recovery Frame



**Carers assessments should be offered to anyone who identifies as a main carer: in-house or by Local Authority**



**Recording: all elements of 3iS must be recorded**



**CFF feedback and evaluation: Feedback should be gained using the CFF Feedback Template at one, three and six months**

# Conclusions

- New recovery paradigm challenges the traditional support model
- Need to have a systemic understanding of recovery in a family context, rather than recovery in isolation
- Major attitude shift regarding inclusion and partnership working
- Experience of care giving evolves over time – families need a broad range of support, skills & competencies

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