

# Combining education, experience and evidence to support families and the PiLaR Programme.

Founder's Day Conference 2018 - Eating disorders  
in a modern society

30th November 2018

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# Outline of today's talk



FIONA  
EVIDENCE



HARRIET  
EDUCATION



INGRID  
EXPERIENCE



# Discloser slide

## **STEDI Research Team**

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PILAR Research funded by HSE





# Parents and Carer Burden in ED

## MH Reform:

- Last 20 years in Ireland: shift in care from in-patient (institutions) to community
- Implicates families more in provision of care
- Participate in treatment, rehabilitation
- May assume the responsibility for the physical, emotional, medical & financial care of the sick relative

## Care Giver Burden:

- Emerging concept in literature
- Physical, emotional, social, and financial consequences experienced by family caregivers
- Objective and subjective components
- Burnout: when positive caring changes to negative and unconcerned
- Compassion fatigue

## Determinants of Caregiver Burden:

- Disease-related factors:
  - Duration of illness, no. of hospitalizations, degree of functional impairment, presence of neuropsychiatric symptoms, crisis situations or problem behaviors
- Clinical and socio-demographic factors:
  - Patient: young, male, comorbid mental & physical illness
  - Caregiver-older age, female, low household income, low level of education, degree of kinship with the patient, illness in caregiver,
- Social psychological factors
  - low social support, family dysfunction

## Some evidence

- Higher scores of overload in caregivers of psychiatric patients when compared to other conditions
- Higher within MH disorders, higher in ED.



# Parents and Carer Burden in ED

## Eating Disorders

- Start early: 86% cases onset before age 20
- Persist: Average duration 6 years
- Associated morbidity & mortality
- Treatment primarily community based & Parental responsibility to refeed : FBT

## Importance of looking after Carer :

- Family factors contribute to outcome
  - Act as support & resource for YP
  - Contribute to or maintain ED pathology, via high EE, conflict, accommodation etc
  - Family dysfunction can reduce effectiveness of & engagement with treatment

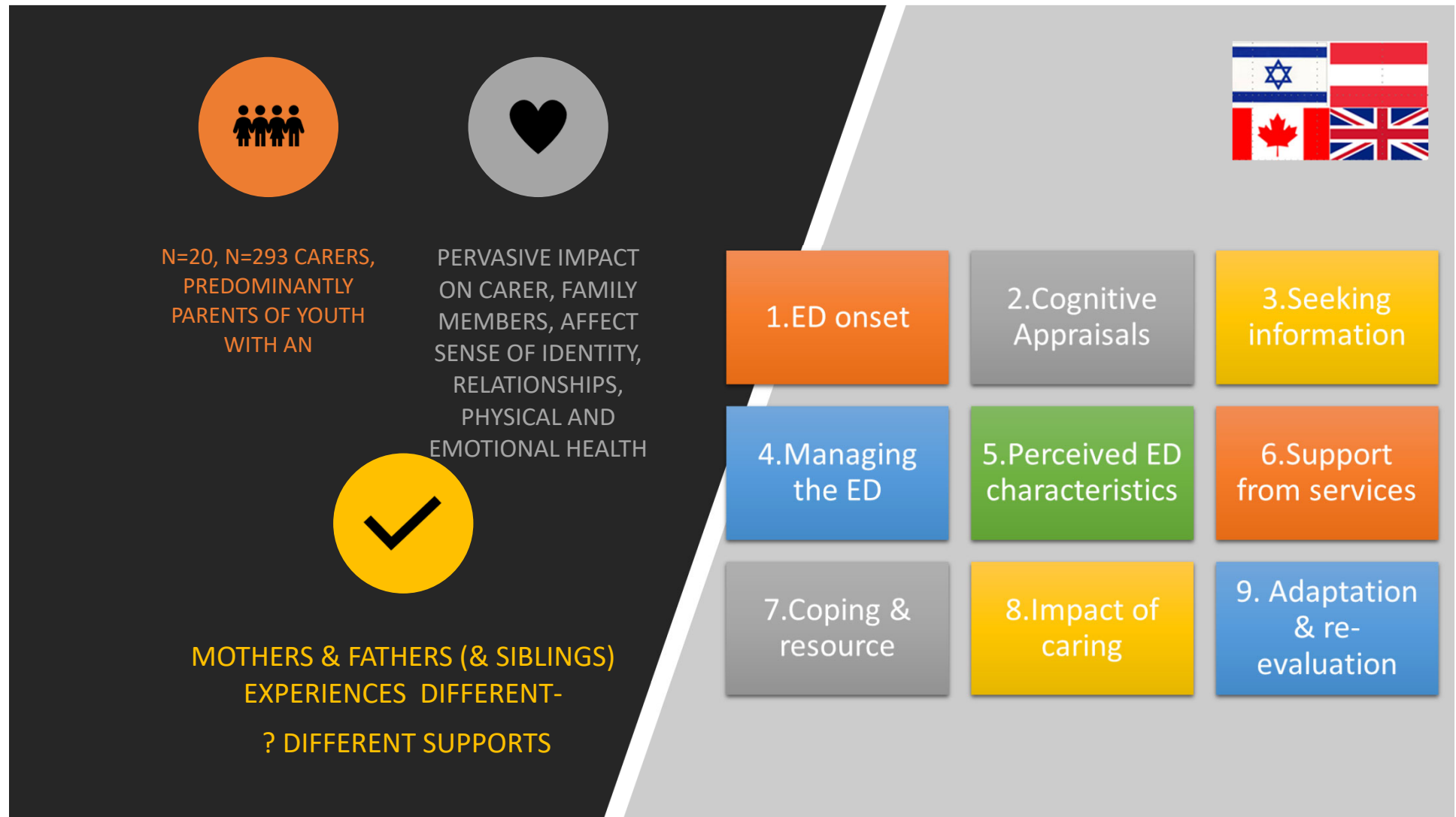
## Carer Burden:

## Literature predominantly qualitative & emerging

- Systematic Review (Zabala, MacDonald & Treasure, 2009)
  - Few studies (20)
  - High levels of psychological distress, burden of care & high EE
  - Unclear if specific to ED
    - Some found effects more significant than other mental illness



# Meta Synthesis of Qual studies on carer's experience (Fox et al, 2017)





# The Experience of Caring For or Living with an Individual with an Eating Disorder: A Meta-Synthesis of Qualitative Studies

John RE Fox,<sup>1,2\*</sup> Madeleine Dean<sup>2</sup> and Anna White<sup>3</sup>

<sup>1</sup> Department of Psychology, Royal Holloway, University of London, Surrey, UK  
<sup>2</sup> Enfield Complex Care Team, Barnet, Enfield and Haringey NHS Trust, London, UK  
<sup>3</sup> School of Psychological Sciences, University of Manchester, Manchester, UK

**Controlling & immobilising effect on family**

Partners and siblings: few resources, feel stigmatised

Wish to protect sibling

Social disruption – lost relationships

Personal culpability & ignorance

Feeling – ‘shut out’  
self blame & guilt

Support groups highly valued

Informal networks invaluable but lacking knowledge

Specialist resources – knowledgeable but lacking time, hard to access

Anxiety, depression, grief  
Guilt, exhaustion, insomnia, hopelessness

Emotional support – including to siblings

Struggled to find info

Practical support – negotiating health care systems

‘Desperately’ seeking info ‘from everywhere’



# STUDY on YP, carers & clinicians: STEDI

## *Journey from Parent- Carer:*

2014: SJOG funded multi-perspective study

- A case-study approach
- 1-1 semi-structured interviews
- Recruited nationally & via clinics
- GT approach & analysis

Young person (N=8)

**Parents (N=7)**

Clinician (N=3)

### **Process of Normalisation**

- Emerging Symptoms:
- Normalized as Normal Adolescent development
  - Pursuit of healthy lifestyle
  - Supporting adolescent autonomy
  - Easy to understand - 'Normative discontent'
- Family values
  - Healthy household
- Provides temporary protection, reduces their significance

Irish Journal of Psychological Medicine, page 1 of 9. © College of Psychiatrists of Ireland 2015  
doi:10.1017/ipm.2015.66

ORIGINAL RESEARCH

### **Eating disorder services for young people in Ireland: perspectives of service providers, service users and the general adolescent population**

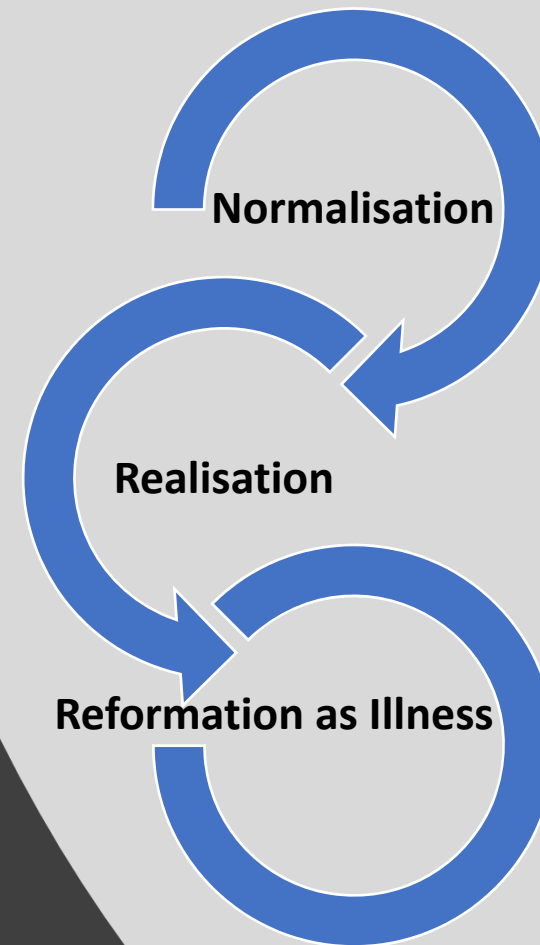
F. McNicholas<sup>1,\*</sup>, C. O'Connor<sup>2</sup>, N. McNamara<sup>3</sup> and L. O'Hara<sup>1</sup>



# The journey from parent to carer:

- **Prompted by:**

- Visual reality
- Impairment:
  - Medical / physical complication
  - School related issues
  - Social isolation





# Normalisation to Realisation

*And at that time,.. I thought, okay, she's told me, I spoke to her, em...everything will be fine, that's what I thought. And every now and again I'd say to her ...are you okay? And then, I didn't know whether to talk about it, not talk about it, mention it to her, bring it up. So I left it then, so to me she was fine... She was cured. And about six months later, about six months later it was em...she said 'mam I'm after been sick again'... And my whole world fell apart*





*it was one particular session with the counsellor,... she rang me after the session and she said to me em,... 'she's slipping away, we have to catch her quick'... And this was for me an alarm call,.. you know and em, first of all I contacted my GP to make, you know, blood samples.... And I contacted my em, therapy friend ....again to get another contact quick, ....something good.*



## The journey from parent to carer



REALISATION

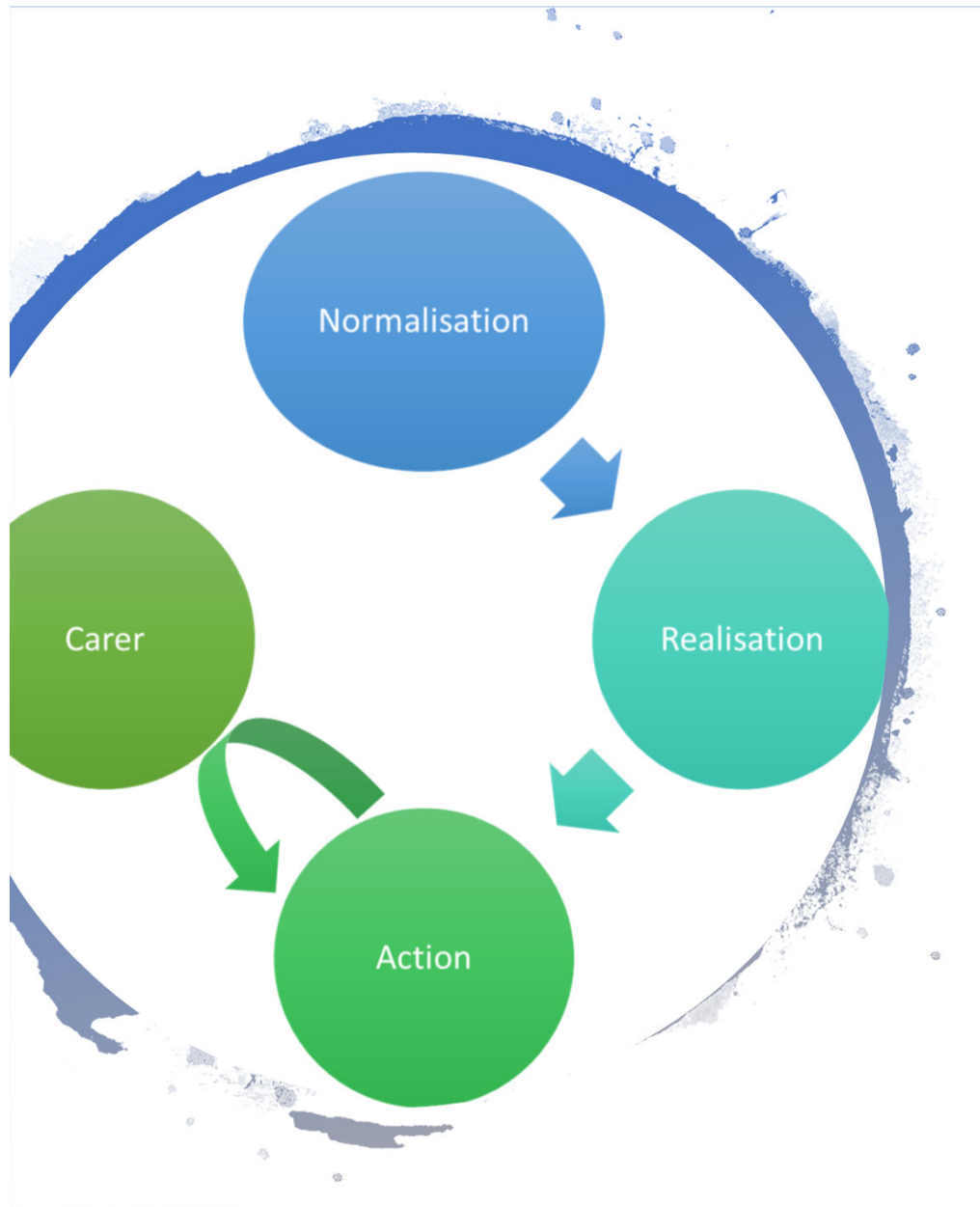


ACTION



IMMEDIATE  
PURSUIT OF  
TREATMENT





## The journey from parent to carer

- Parents Described feelings of:
  - Stress/Anxiety/depression
  - Consumed by Illness
  - Ill-equipped
  - Alone/Unsupported
  - Personally responsible
- Reported
  - Personal, Social & Family Identity change
- Balance between
  - Recovery-supportive environment for YP and family
  - Restoring family group





# Being a Carer:

Mother of 15 year old boy with BN

- 
- So since he was discharged (after 6 weeks of inpatient treatment) how has the care been since then?
  - Hopeless
    - It's not, there is **no care**, there's **no outlet or outreach** that we could go, ...like I tried myself to try and get somewhere, ...**there is nowhere**. I asked my GP can you put me, ...because I really thought I was losing my mind, I wasn't sleeping, ...because I was watching him the whole time. ....I said can you put me in some kind of a counselling session or, ...He sent me to a stress management clinic, I said I don't want to go to, ...I don't need a stress management clinic,... ***I need someone to talk to that understands ED*** which my son has got. And I said **it has affected all of us**.
  - **But there is nowhere, there is no help.**





Alone

Hopeless

Despair

## Being a Carer:

Mother of 15 yr old girl with AN

*I mean, it **affects everybody** in so far as that, like I would have gotten more stressed, kind of over, especially the first few months.....it was very stressful (upset), ....like **it was really stressful**, ...you know to see her ..like just going to sleep with hunger, ...do you know like she'd be, ..like lying in the bed and she was just tiny ...and its just like,... just **feels so like nobody will help her**, really, do you know.*

*And **when its just you**,... just you know and then, so you'd be very upset for a while and then, I suppose the other kids... **you just don't have as much time.***



# Conclusions & Implication

- Initial normalisation followed by hurried help-seeking
- Life (family-life) is consumed by ED
- Isolated and unsupported in role of carer

## WHAT CAN WE DO?

- Need to raise awareness of ED in order to reduce delays in help-seeking
  - Create an ED HUB: HSE-UCD-Bodywhys
- **Greater support for parents & families**, bearing in mind fathers, partners and siblings as well as mothers, including identity changes
- HSE
  - Family, carer & Supporter guide
  - National Clinical ED programme
- PILAR Program: Bodywhys
- Interesting RCT:
  - SUCCEAT Austria 8 workshops/online or TAU.
  - Franta et al, 2018



ED HUB







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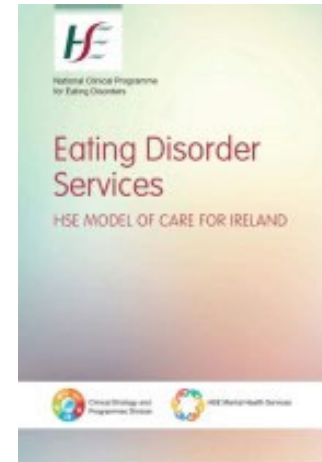


INGRID  
EXPERIENCE



# Bodywhys: The Patient's Voice

- Supporting people affected by EDs in Ireland
- Experience on the Support Services – demand for more!
- PiLaR Pilot programme
  - Pilot Sligo
  - Launched Limerick (2014)
  - **23** Locations Nationwide
  - Over **600** people attending
  - Supporting the National Clinical Programme



Programme  
for families & friends  
supporting someone  
with an eating disorder

PiLaR : Peer Led Resilience



# Family Expectations

2014

- To learn about eating disorders and recovery.
- To gain insight and understanding.
- How to help my family member, where to get help and information
- To get personal support and seek reassurance.
- How to cope with emotions and how to remain calm in stressful situations

2018

- To understand better how I can support without being over-anxious and dominated by the disorder
- Coping skills / How to help my daughter / Support
- To become more informed so as to be more supportive
- Understanding and patience for him, to keep supportive
- To learn / cope
- To hear from other parents



# What we hear families want



Information



To understand



How to  
support in a  
helpful way



Understand  
the mindset of  
a person with  
an ED



What does it  
mean that an  
ED is not just  
about food?



How can they  
be resilient?



To ask about  
treatment...



To have a space for themselves to be  
able to say how hard they find it,  
how frustrated they are, their lack of  
understanding and how it frustrates  
their efforts



# PiLaR Programme: Supporting Families



## **Week 1**

Understanding  
Eating Disorders



## **Week 2**

Understanding  
how a PWED  
interprets their  
world, avoiding  
power struggles,  
communication



## **Week 3**

Managing  
mealtimes, family  
life and siblings,  
coping with  
special occasions,  
coping with  
routine, managing  
triggers



## **Week 4**

Recovery,  
treatment,  
support



Who  
attends?

**Parents (Mother 57%, Father 30%)**

**Siblings (Sister 3%, Brother 1%)**

**Extended family (Cousin 3%, Aunt 2%,  
Grandmother 1%)**

**Partner 2.5%**

**Friend 0.5%**



Who are  
they  
supporting?

Daughter 76%

Son 12%

Sister 4%

Niece 2%

Wife 3%

Brother 1%

Cousin 1%

Grandson 0.5% & Granddaughter 0.5%



How many  
family  
members  
attend?

**1 person 57%**

**2 people 39%**

**3 people 3%**

**4 people 1%**



Type of Eating  
Disorder  
(81% in  
treatment)

**Anorexia 71%**

**Bulimia 18%**

**BED 4%**

**AN/BN 4%**

**Other 3%**





## Pilar Testimonials...

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A course like this should be compulsory – when referral is made to CAMHS, this course should be offered during the waiting time. Empower parents / inform them / help them.

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This was a brilliant course. Very Informative. Very professionally run. Course notes are excellent. Thank you so much for your knowledge. Parents are left floundering trying to cope with a child with an ED with no knowledge or clue on how to support the child. This course should be run more often and CAMHS should be telling parents about this service you run. I truly enjoyed coming to each session.





## Pilar testimonials..

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A course that if at all possible, you should try to attend if you are carrying or living with someone with an eating disorder. It is a huge help to understand and accepting that the person has an eating disorder

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I am a parent of a young girl with anorexia. The course has been the best source of education on the eating disorder and it helped me to appreciate how my daughter is feeling. It is helping me to deal with the challenges we are facing in a better way





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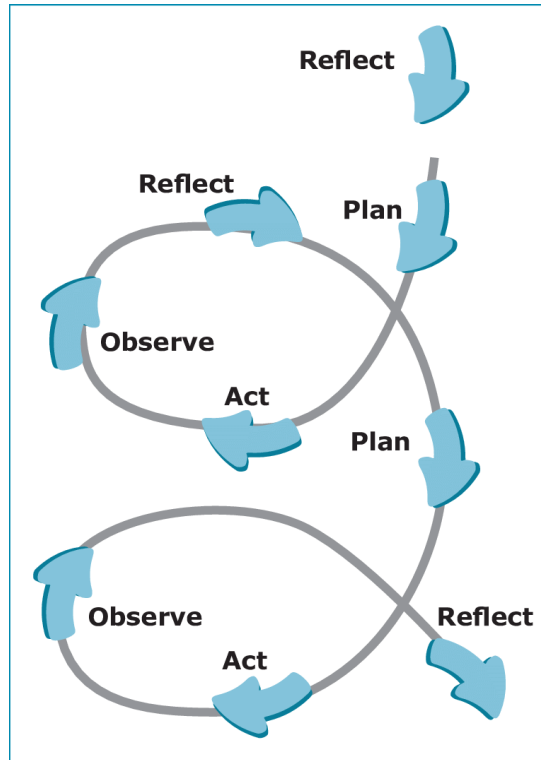


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EXPERIENCE





# Collaboration between Bodywhys, HSE and UCD

PILAR research team:

Dr Ingrid Holme (UCD)

Harriet Parsons (Bodywhys, HSE)

Ms Rhona Jennings & Dr Sara McDevitt (NEDCP, HSE)

Prof Fiona McNicholas (SJOG, UCD, & OLCHC)

1st cycle

Adapting Monitoring and Evaluation

Capturing Experiences of PiLaR

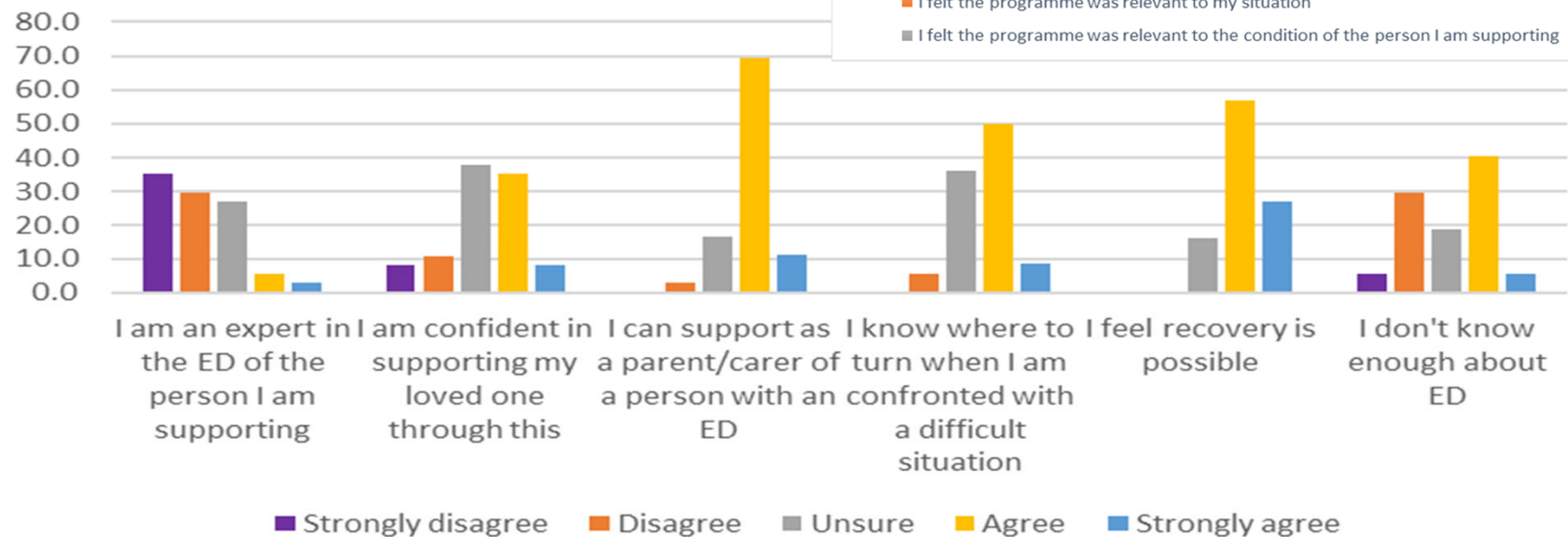
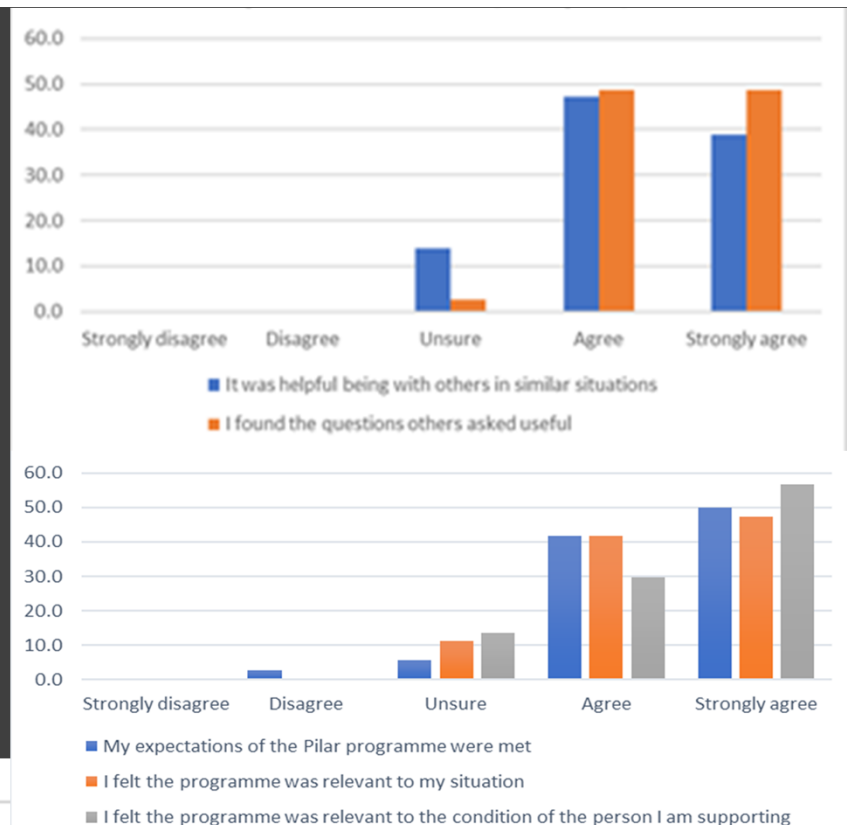
Lê G, Huss R, Mshelia C, Mirzoev T (2015)

"How to use Action Research to Strengthen District Health Management: A Handbook" Leeds: PERFORM Consortium (PDF) How to use Action Research to Strengthen District Health Management: A Handbook.



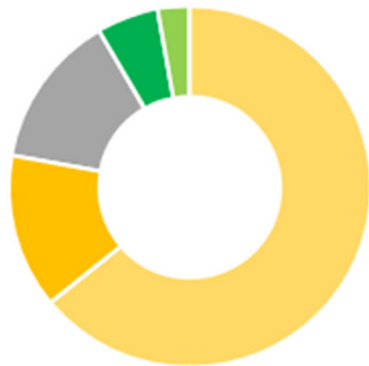
# Monitoring data

- Week 1 and 4: way of analysing the trends in effects and impact of the project
- Shapes the next cycle

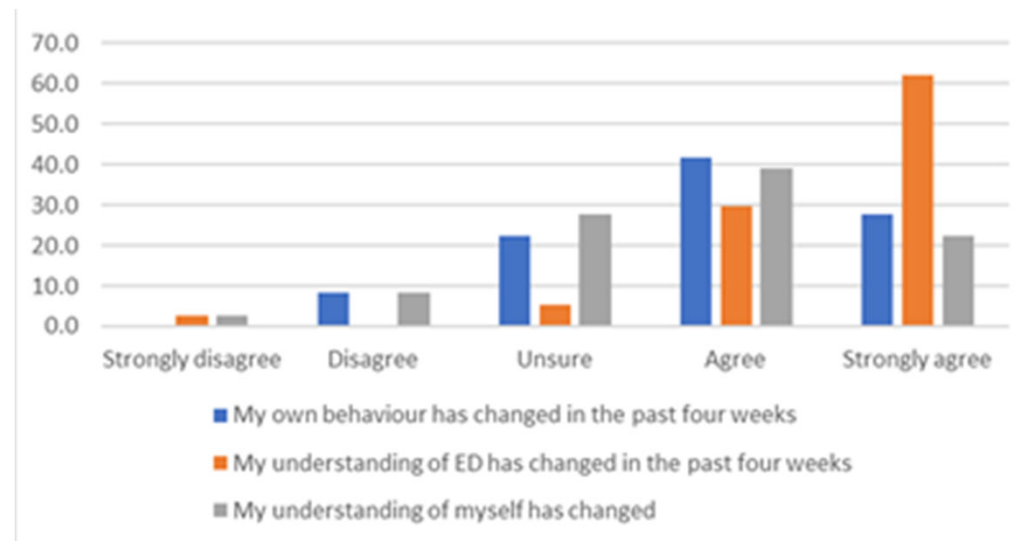





# Mental Health needs of supporters



Strongly disagree Disagree Unsure Agree Strongly agree







## The right type of information

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At that time, I was just a sponge and said, 'Give me everything I have,' and getting to [location], which is where I did the PiLaR programme, was a pain in the arse, but I said, 'I don't care, it has to be done,' so I made that commitment to go for the four weeks.

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they send me out leaflets and, oh, leaflets, shmeaflets, do you know what I mean? You could've written them yourself. Like, no offence to Bodywhys, but there was nothing in them that I didn't already know. So, I, kind of, put Bodywhys to the back of my mind and thought, 'That's not really what I need.'



## Becoming an expert

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Somebody said to me, 'You must be an expert on anorexia now,' and I'd say to them, as I always say to people, I said, 'I'm an expert on my daughter's anorexia alone,' but everyone's is different, unfortunately. There's a pattern and that's, I thought Harriet was amazing. The first time I sat there, she was describing this and that, and this behaviour and that pattern, and I was, like, 'Oh, my God, it's just like living with her. She must know her.' Incredible. She had amazing insight into the illness.

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We found ourselves in this eating disorder world where we knew nothing about it. So, they were very, you know, happy to say to us, 'Look, this is something you really, really need,' and I suppose we didn't have a lot of support at the time except for the team in CAMHS, you know.



It was very good. There was a lot of good information. They gave us a good insight into how the anorexic person or eating disorder person is actually thinking, which was good because we had different opinions about that, like everybody else who has a daughter or someone with an eating disorder, we just thought they'd chosen to do this. You know, sometimes you want to give them a good kick up the arse and just, 'Bloody eat.' So, it really opened our eyes to the fact that it's really something they have a huge amount of control over, and we had a lot more sympathy, I think, probably.





## Next steps

What engagement  
is required with  
which  
stakeholders

Do the current  
monitoring tools  
produce the data  
we need?

How do we  
achieving fit  
between PiLar and  
ED services over  
the next five years

What are the  
professional views  
of the  
programme?



Thank You



Go raibh míle maith agat



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## Acknowledgments

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- SJOG Funders & study team
- Study participants, Bodywhys & Staff CAMHS



# Additional slides

Notes:



# DETAILS OF THEMES FROM Fox et al.

1. ED onset:
  - Gradual realisation delayed by misattributions (normal adol phase), secrecy, professional ignorance
  - Initial impact: predominantly self blame & guilt
2. Cognitive Appraisals:
  - Carer sense of Personal culpability & ignorance
  - holding simultaneous contradictory views: 'choice' or 'uncontrollable',
  - Appraisals changed over time & directs carer behaviour
3. Seeking information
  - 'Desperately' 'from everywhere'
  - Struggled to understand it
  - Wish to protect siblings
4. Managing the ED
  - Practical support (negotiating the health care systems)
  - Emotional support (including to siblings)
  - Accommodation & enabling (avoid conflict, upset)
  - Direct & indirect approaches to manage behaviour)
5. Perceived ED characteristics
  - Resistance to change
  - Negative: controlling, dominating family life
  - Vulnerable: risk death, lost opportunity, lost relationships
6. Support from services
  - Difficulty accessing, personal cost, mixed perceptions
  - Feeling-'shut out' 'excluded'
7. Coping & resource
  - Informal networks invaluable but lacking knowledge
  - Specialist resources knowledgeable but lacking time, hard to access
  - Support groups highly valued
  - Partners and siblings: few resources, feel stigmatised
8. Impact of caring
  - Positive: but gen coexisting with neg: empathy, increased family alliance, more insight
  - Severe strain on carer emotional wellbeing: anx, depression, exhaustion, insomnia, hopelessness, grief, guilt,
  - Negative impact on siblings, partner, all family via pervasiveness, conflicts, realignments
  - Social disruption
9. Adaptation & re-evaluation:
  - New parenting approaches (& appraisals) based on experiences & knowledge
  - Iterative process leading to adaptation, new acceptance, less emotional over involvement, reduced EE into 'illness model'



# Eating disorder services for young people in Ireland: perspectives of service providers, service users and the general adolescent population

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<sup>2</sup> Department of Psychology, Maynooth University, Maynooth, Co Kildare, Ireland

<sup>3</sup> Division of Psychology, Nottingham Trent University, Chaucer Building, Burton St., Nottingham, NG1 4BU, UK

**Objectives.** This paper illuminates how national eating disorder (ED) policy translates into day-to-day practice by exploring how ED services are experienced by those who deliver and use them.

**Methods.** A mixed-methods approach was used, which combined qualitative and quantitative techniques. The paper collates data from three studies: (i) an interview study exploring the lived experiences of young people with EDs ( $n = 8$ ), their parents ( $n = 5$ ) and their healthcare professionals ( $n = 3$ ); (ii) a national survey of health professionals' perspectives on existing ED services ( $n = 171$ ); (iii) a nationwide survey of secondary-school students' eating concerns and patterns of help-seeking ( $n = 290$ ).

**Results.** The qualitative interviews with young people and their parents revealed feelings of isolation and helplessness. Young people expressed interest in patient support groups, while parents desired greater support for the family unit. Parents were highly critical of available services, particularly in relation to access. These criticisms were echoed in the survey of healthcare professionals, who reported many barriers to delivering effective care. Clinicians were almost unanimous in calling for care pathways to be clarified via a standardised treatment protocol. The survey of adolescents indicated widespread reluctance to seek help regarding eating concerns: over one-third expressed concern about their own eating habits, but half of these had not divulged their concerns to anyone. Participants' preferred pathways of help-seeking revolved around family and friends, and adolescents were unsure about routes of access to professional support.

**Conclusions.** The research demonstrates that many aspects of national ED policy have not been implemented in practice. The paper highlights specific gaps and suggests ways they can be redressed.

*Received 9 June 2015; Revised 19 November 2015; Accepted 24 November 2015*

**Key words:** Eating disorders, interviews, mental health services, surveys, youth mental health.



## Stigma and treatment of eating disorders in Ireland: healthcare professionals' knowledge and attitudes

F. McNicholas<sup>1,2,\*</sup>, C. O'Connor<sup>2</sup>, L. O'Hara<sup>1</sup> and N. McNamara<sup>3</sup>

<sup>1</sup> *School of Medicine & Medical Science, University College Dublin, Belfield, Dublin, Ireland*

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**Objectives.** This study examines aspects of healthcare professionals' knowledge and attitudes about eating disorders (EDs), which might impede the effective detection or treatment of EDs in Ireland.

**Methods.** A total of 1,916 healthcare professionals were invited to participate in a web-based survey. Participants were randomly allocated to view one of five vignettes depicting a young person with symptoms consistent with anorexia nervosa, bulimia nervosa, binge-eating disorder, depression or type 1 diabetes. Study-specific questions examined participants' responses to the vignettes and ED knowledge and experience.

**Results.** In total, 171 clinicians responded (9% response rate). Participants had an average of 15.8 years of clinical experience (s.d. = 9.2) and included psychiatrists, GPs, psychologists and counsellors. Although participants' knowledge of EDs was moderately good overall, responses showed poor recognition of the symptoms of EDs compared with depression [ $\chi^2$  (4,  $n$  = 127) = 20.17,  $p$  < 0.001]. Participants viewed EDs as chronic disorders that primarily affected females. Participants believed that clinicians like working with patients with depression and diabetes more than with AN patients [ $F$  (4,101) = 5.11,  $p$  = 0.001]. Among the professionals surveyed, psychiatrists were the most knowledgeable about EDs [ $F$  (4,82) = 9.18,  $p$  < 0.001], and were more confident in their ability to diagnose and treat EDs than professionals of all other disciplines, except psychologists [ $F$  (4,85) = 8.99,  $p$  < 0.001]. Psychiatrists were also the most pessimistic about ED patients' long-term life prospects [ $\chi^2$  (4,  $n$  = 65) = 15.84,  $p$  = 0.003].

**Conclusions.** This study recommends that specific attention should be given to EDs in professional educational programmes across healthcare disciplines. This training should not be restricted to improving healthcare professionals' knowledge of EDs, but should also strive to increase service-providers' awareness of how their own potentially stigmatising attitudes can undermine engagement with treatment.

*Received 19 December 2014; Revised 8 April 2015; Accepted 21 April 2015; First published online 22 May 2015*

**Key words:** Attitudes, eating disorders, health professionals, knowledge, stigma, youth.



## The GP's perspective: they want support as well!

“I would prefer if I had better and more, better resource to referral options. Eh and better structures, shall we say, for the different age tiers that we encounter. ‘Cos in reality they, they’re not there, eh, and what services we have there are stressed. So some respects they’re on paper only, where you might look for prompt intervention, what you might achieve is someone going on a waiting list. Which is, less than ideal, you know, it’s, it’s a resource issue, you know. But resource and perhaps, also a sufficiency of expertise in the field, you know. For us as GP’s, I wouldn’t regard myself as any, having any particular expertise in eating disorder, other than to recognise it. And perhaps offer some form of support, that’s something I would refer very early on in the cycle, as a GP.”



## Questions you might want to ask

The following are some of the questions you might want to ask:

- What diagnosis has my relative and what does it mean both in the short and long term?
- Will they have to go to hospital and, if so, how long are they likely to be there?



- Will there be aftercare follow up after they have been discharged?
- Will they have to take medication and, if so, for how long?
- Will my relative be put on a therapeutic programme and, if so, when might it start and how long will it last?

- What involvement can we as family members or supporters have, for example, in their Care Plan?
- What can I do to help and support?
- Where can I go for help and support?
- What sort of challenges might I face when my relative comes home?

## Medication

Medication can play a significant role in the clinical recovery of a person dealing with mental health difficulties.

Here are some questions that might be on your mind about medications.



- What medication is to be used?
- How often will the medication be re-viewed?
- How long will the medication have to be taken for?
- Are there other medications that could be used if this one doesn't work?
- What will happen if they stop taking the medication?



## Notes

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## Complaints

If you would like to make a complaint, you should approach an appropriate member of staff informally as often complaints can be addressed there and then. If you are not satisfied, you can use the more formal procedures of the HSE *Your Service Your Say* process. *Your Service Your Say* leaflets and forms can be found in all HSE supported facilities.

## Useful Contacts

HSE Mental Health Choice and Medication Website  
[www.choiceandmedication.org/ireland/](http://www.choiceandmedication.org/ireland/)

Family Carers Ireland Website  
[www.familycarers.ie](http://www.familycarers.ie)

Mental Health Engagement Website  
<https://tinyurl.com/Mental-Health-Engagement>



Mental Health Services

**Family, Carer and Supporter Guide**