



College of Psychiatrists
of Ireland

Wisdom • Learning • Compassion

REFOCUS

Recovery Experience Forum of Carers and Users of Services

ANNUAL REPORT 2018



"For me the wild honeysuckle is my connection to the past, growing up on a farm in rural Ireland. Everything has a season and this represents spring which holds a lot of possibilities and is a time for growth and renewal."

Julie Cleere - Artist & REFOCUS Member

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FOREWORD



I have been a member of REFOCUS since 2011 and had the honour of being elected as Joint Chair in February. 2018 has been a very busy and productive year for REFOCUS with lots of invitations to participate in College Conferences, the Foundation Year Trainee Induction, and many other activities including making a presentation to the College Advisory Board. The committee also participated in two education sessions for Oireachtas members and staff at Leinster House in February and great interest was shown in our work by those present.

In June some of the members of REFOCUS attended "Mind-Reading: Mental Health and the Written Word" in Birmingham University hosted by both UCD and St Anne's College, Oxford which gave the group an opportunity to expand its profile.

I consider the most valuable asset of the group comes from the vast experience of its members. This has been acknowledged by the College and is evidenced in the various papers and perspectives produced by the group over the years. The group is currently working on perspectives around Family Dynamics, Spirituality (its place in mental illness), Psychiatric Diagnosis, and more recently on a project on the monetary impact of mental illness.

At our December meeting we had a "brainstorming" session where the group reflected on what REFOCUS has achieved and valuable suggestions were made on how we can continue our work and engage with the College and other stakeholders.

In 2018 one of our members and previous Joint Chair, Kevin Jones, stepped down from the committee. I want to thank Kevin for his dedication to the work of REFOCUS and wish him well for the future.

In December Dr Anne Jeffers, Joint Chair of the committee also stepped down. I want to thank Anne for her constant commitment and dedication to the work of REFOCUS. Anne was instrumental in forming this group and indeed it was through her vision and belief in the value of service users and family members that has made REFOCUS the success it is now. On behalf of REFOCUS I want to wish her the very best for the future.

Dr Mia McLaughlin replaced Anne as Joint Chair and I look forward to working with Mia in the future. I wish also to thank the College EAP Team, Andrea Ryder, Mary Hayes and Jennifer Farrell for their support and hard work during 2018.

Finally, I want to thank all the members of REFOCUS for their support, and for their commitment to the work of REFOCUS. I look forward to working with and for the group in 2019.

Ms Christine McCabe
Joint Chair



FOREWORD (CONT'D)



Along with my Joint Chair Christine Mc Cabe, I am delighted to present the 2018 Annual Report for REFOCUS. As Christine describes, 2018 was another busy year where REFOCUS members took part in many College events and represented the College in external events.

One of the highlights for me was when one of our members and myself presented at the College's NCHD conference. The member spoke of the difficulty he experienced when, during a psychotic episode, the doctors he was seeing at the clinic did not pick up on the fact that he was psychotic. One of the audience members asked what advice he had for doctors in working with people who were not accessible because of psychotic symptoms. He quite simply stated he had no difficulty communicating with his wife and even when he was very paranoid and experiencing psychotic symptoms, he still trusted her and accepted she wanted what was best for him. She also recognised when he was relapsing. If doctors could develop a relationship of trust with their patients that would ensure effective communication. Very simple – but so true.

As Christine has stated, I have stood down from REFOCUS and I am delighted that Dr Mia McLaughlin has now taken on the role of Joint Chair. I wish Mia and Christine and the full REFOCUS committee ongoing success.

As this is my last input into a REFOCUS Annual Report I would like to leave some reflections. I have spoken in other reports of the valuable experience for me in sitting with the members of the committee – all of whom have been committed to one aim – finding a way to improve the mental health services, and through REFOCUS influence the training and practice of psychiatrists. Whether it was that we had such a clear focus and remit, whether it was that almost all the committee have had many years of self-improvement, or it was just chance that we had such a great group of people working together – but REFOCUS has been one of the most productive and worthwhile groups I have ever experienced. I personally gained added insights into working with individuals and families and my only regret is that more psychiatrists do not benefit directly from the work of REFOCUS. We have written papers to help give further insights for all psychiatrists and I would particularly pick out On the One Road to Recovery as an example of what psychiatrists can learn from service users.

Just as most of us experience in clinical practice, I have found all REFOCUS members to be very kind and caring towards us, their psychiatrists. They appreciate the work we do, our expertise and how we care and advocate. They have expressed concern that we do not include enough self-care into our working life. Yes, they are critical of aspects of their care and of poor resources and in REFOCUS they are willing to work with us in improving services. It is important that we are open to hearing how we can improve services and welcome the messages coming from service users and family members/carers. REFOCUS has been an active committee of the College for the last seven years. It is welcome that one of the Joint Chairs is a member of College Council and I look forward to the day that both joint chairs are members of Council, and College members will benefit directly from service user expertise.

Dr Anne Jeffers
Joint Chair



INTRODUCTION

This report encompasses the work of REFOCUS throughout 2018. It follows on from the Committee's Annual Reports of 2015, 2016, 2017 and the REFOCUS Inaugural Report 2011-2014. REFOCUS has continued to thrive through its dynamic group discussion, well-structured meetings and interaction in various ways both within and outside the College. The Committee is considered to be an invaluable resource within the College as is evident in this report.

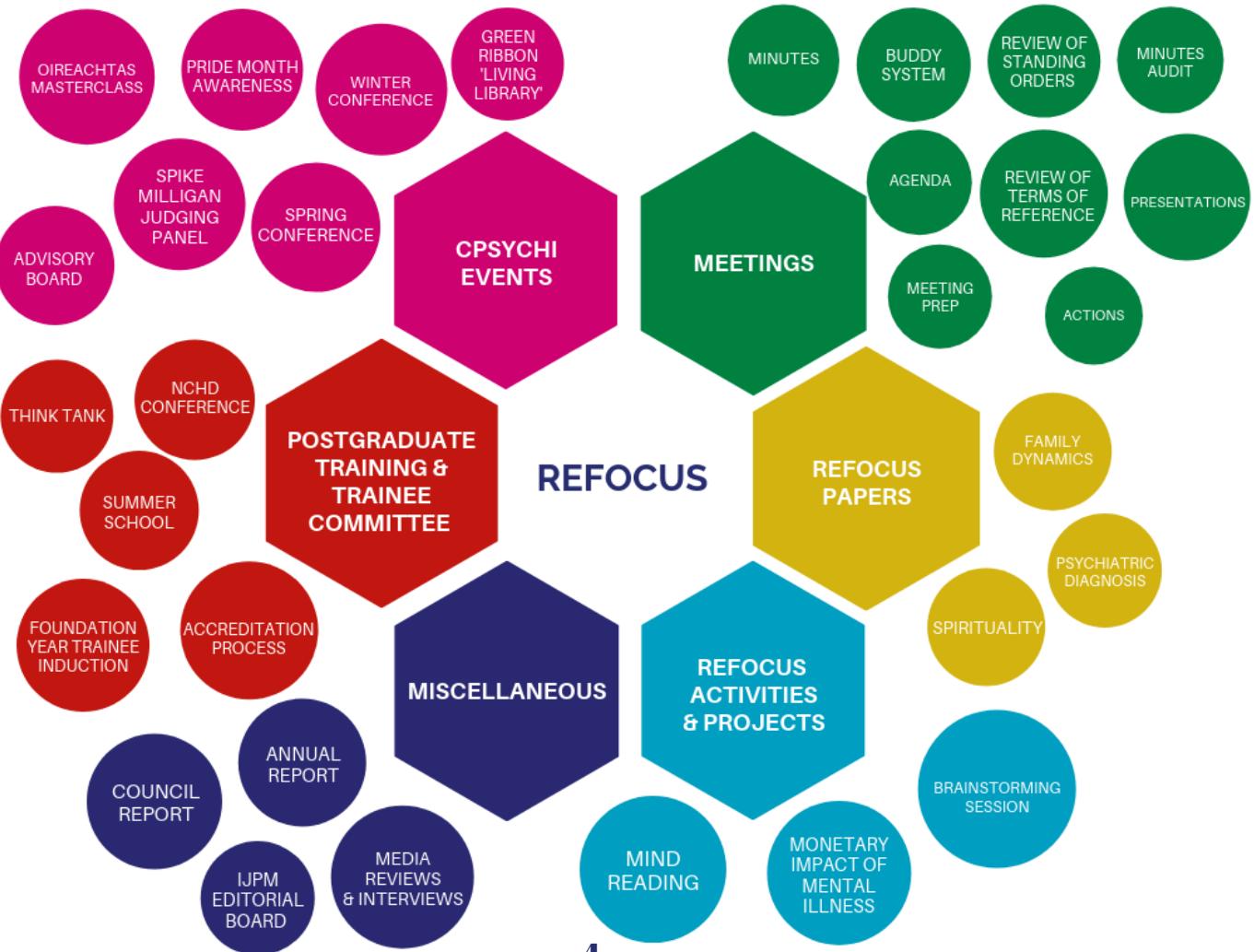
REFOCUS

REFOCUS stands for Recovery Experience Forum of Carers and Users of the Services, reflecting the strong belief of the forum in the wellness and Recovery philosophy.

REFOCUS is a forum where the views of people with experience of using the Mental Health Services, and family members and carers of those who have used the services, aim to inform and influence all aspects of College business particularly the training experience of young future psychiatrists and identifying ways to improve the mental health services with psychiatrist members. This ties in with the College mission to promote excellence in the practice of psychiatry including advocating for better services.

“REFOCUS is an effective example of carers, services users and professionals working together with mutual respect and understanding, a safe place of acceptance.”

The name REFOCUS reflects what concerned the group, which was the need to inform the College and its various committees and training programmes, not only about the experience of those who use the Mental Health services in Ireland and their family members/carers, but also to provide suggestions for change and improvement. The idea of "refocusing" seemed to capture this objective perfectly.



MEMBERSHIP OF REFOCUS

The group originally comprised of 10 people with experience of the Mental Health services and 10 Carers/Family Members of those who use the services, as well as Chair and Consultant Psychiatrist Dr Anne Jeffers. In 2016 it was decided that the group and the College would benefit from the inclusion of psychiatrists; both trainees and specialists. Having a mix of those with experience of the services, their family members and carers, and psychiatrists on the committee allows the group to accurately reflect the actual life situations of all parties involved when someone is unwell. It also contributes to rich and meaningful discussion and subsequent activities to support the aims of REFOCUS. The committee now has 8 people with experience of the Mental Health Services, 8 Carers/Family Members, and 8 Psychiatrists.

REFOCUS welcomed new members Dr Caoimhe Clarke and Dr Tiago de Castro Gomes, both trainee psychiatrists, who joined in 2018.

The committee also voted to appoint Christine McCabe as the new Joint Chair in February 2018.

In December 2018, the Committee bid farewell to Dr Anne Jeffers, who stepped down as Joint Chair of the committee. Anne was instrumental in forming REFOCUS and her constant commitment and dedication to the work of REFOCUS cemented the committee's place in the College, ensuring the voices of those who have used the services and their family members are heard. Her vision of the committee made the committee what it is today.



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REFOCUS is a cohesive group, bonded through shared experiences.

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REFOCUS bids farewell to Dr Anne Jeffers, former Joint Chair of REFOCUS, at the December meeting

GOVERNANCE AND HOUSEKEEPING

Terms of Reference

REFOCUS continued to use the terms of reference established by the group and reviewed these in 2018. The group has also held firm on its early decision that all members of the forum would participate on an equal basis and there would be no sub group dividing members into those who use the services and family members/carers. The minutes of every meeting are recorded and presented by the Joint-Chairs to the Director of Communications & Public Education.

Standing Orders

In 2016 the committee established Standing Orders to ensure and encourage orderly and effective conduct of meetings with the aim of maximising the output from the limited number of meetings and sub group meetings that take place per year. The Standing orders were reviewed in 2018.

Buddy System

Often REFOCUS meetings entail difficult discussion on sensitive and personal topics. In 2017 the committee decided to establish a 'buddy system' of support so committee members can access help from their peers following these types of discussions. Two people from the committee volunteer at the beginning of each meeting to be available for other committee members to speak to if needed. The committee continues to use this system to support one another.

One of the main achievements of our committee has been meeting many of the aims and objectives set out by the group and the recognition received from the College..



REFOCUS meeting, September 2018

PRESENTATIONS MADE TO REFOCUS

From its inception, the forum felt that it would be helpful if psychiatrists, including trainee psychiatrists from the College membership and other stakeholders, presented to the committee about various psychiatric specialties and/or services in Ireland. The aim of this is to inform and educate REFOCUS members about the psychiatry profession, how psychiatrists operate within the system, mental health teams and so forth. As a result, the committee has had a number of very useful and informative talks.

February 2018

Following invitation from the Trainee Committee for REFOCUS to be involved in the accreditation process and a presentation by Dr Aoibhinn Lynch (CPsychI Chief Examiner) on the accreditation process in December 2017, Dr Anne Jeffers presented on the accreditation visits. Dr Jeffers explained the process of assessing sites where psychiatry trainees train and the importance of this procedure for retaining and supporting trainees.

June 2018

Dr Neil Vickers from the Department of English, King's College London, presented on his research and writing of his book with Derek Bolton, Philosopher and Psychologist from the Maudsley 'Shared Life and the Experience of Illness'. The book aims to think of illness as an amalgamation of a person's life and circumstances. REFOCUS members shared their experiences and insights with him. Dr Vickers said he was fascinated by the rich discussion that took place and thanked the group for their time.

Andrea Ryder also presented on new EU General Data Protection Regulations (GDPR) and what they will mean for REFOCUS.

September 2018

REFOCUS member Laura Louise Condell, who is the coordinator of the Dublin Lesbian Line (a helpline charity which provides support to all members of the LGBTQIA+ community), presented on LGBTQIA+ Awareness and discussed language, history and culture in relation to LGBTQIA+ issues in Ireland. She described her personal experience of living in Ireland being a member of the LGBTQIA+ community and having a mental illness, and the double stigma that these often entail.



Laura Louise Condell of the Dublin Lesbian Line presents to the REFOCUS Meeting, September 18, on the mental health needs of the LGBTQIA+ community.

December 2018

Andrea Ryder presented an update on EAP Department activities which highlighted the main projects undertaken during 2018 with external organisations, including working with Advancing Recovery in Ireland, drafting of a College position paper on Recovery, Family Carers Ireland/UCD School of Nursing, Midwifery and Health Systems/College of Psychiatrists joint survey, and the drafting of the College 'Professional Ethics for Psychiatrists'.

There are many parallels between coming out as gay and coming out with a mental illness to the people around you.

For many LGBTQIA+ people trying to access health services they may not know if a health professional is accepting of LGBTQIA+ people or not... This can lead to them having to edit themselves, which is not conducive to a successful therapeutic relationship...

PRESENTATIONS MADE BY MEMBERS OF REFOCUS

REFOCUS members presented their own work and experience at a number of events throughout the year, most notably at College conferences. REFOCUS members delivered the following:

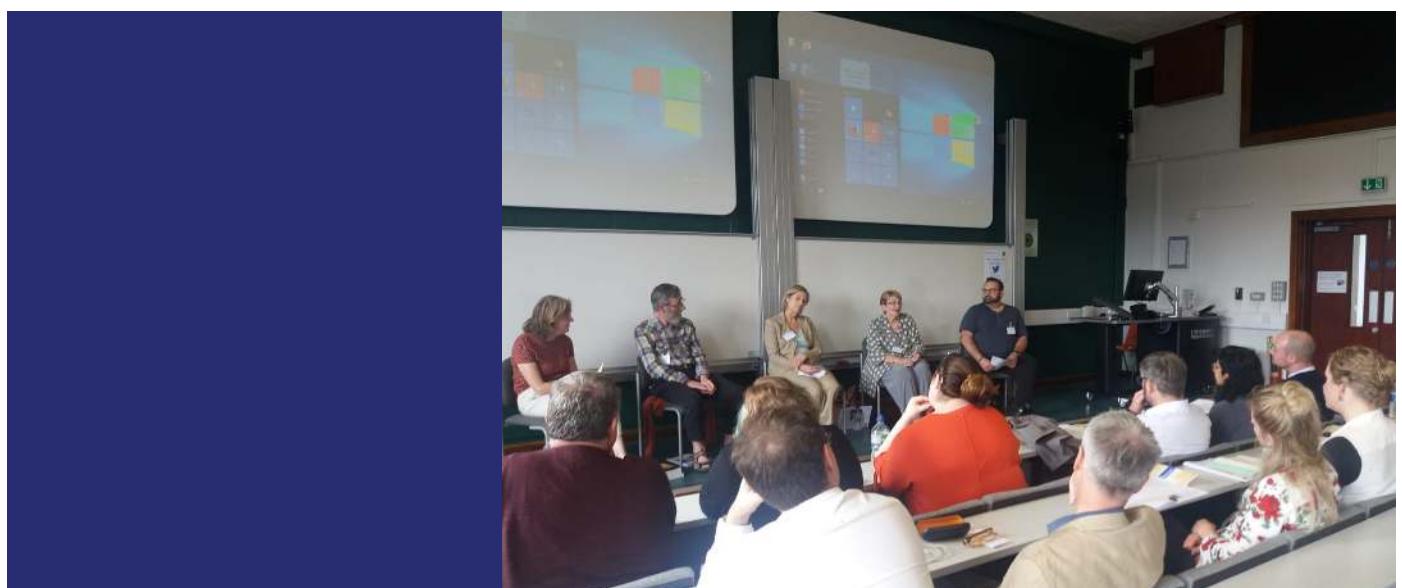


PRESENTATIONS MADE BY MEMBERS OF REFOCUS (CONT'D)

REFOCUS were delighted to be invited, for the second time, to attend the two-day "Mind-Reading: Mental Health and the Written Word" Conference in Birmingham University hosted by both UCD and St Anne's College, Oxford. Rick Rossiter, Christine McCabe, Brian McNulty and Julie Healy delivered a parallel session, chaired by Anne Jeffers, where they spoke about their experience of mental illness, caring for someone with a mental illness and the effect literature has had on this part of their lives.



L-R: Rick Rossiter (REFOCUS), Julie Healy (REFOCUS), Dr Melissa Dixon (Oxford), Dr Elizabeth Barrett (UCD), Christine McCabe (REFOCUS), Dr Anne Jeffers (REFOCUS), Brian McNulty (REFOCUS), Professor Dame Sue Bailey (Chair Children & Young Peoples Mental Health Coalition)



REFOCUS members at "Mind Reading - Mental Health and the Written Word, Birmingham University

REFOCUS PAPERS AND PROJECTS

Papers and projects are borne out of in-depth discussion at the REFOCUS quarterly meetings on areas and issues to highlight to trainees and consultants and in doing so raise awareness of their importance to those who use the services, and their family members/carers. As with all papers that REFOCUS has produced, the committee has and will involve the College membership through the processes and pathway for any College paper.

'Spirituality and its place in Mental Health Practice - Raising Awareness and Being Mindful of Bias'

This paper aims to highlight how some people's spiritual experiences should be regarded with an open mind by mental health professionals when assessing someone and/or devising their treatment plan. The Committee reviewed a video of the same theme made by the Royal College of Psychiatrists and agreed that it adequately communicates the key messages of the draft paper. With the permission of the Royal College, the video was added to the College website and circulated to College members in an eNewsletter.

'Family Dynamics - Ensuring Psychiatrists and Mental Health Teams address Family Dynamics'

The experience of REFOCUS members is that mental health services do not address family dynamics when a member of the family becomes unwell. REFOCUS believes this prevents full recovery for all. This project began as a paper that aimed to identify what happens when family dynamics are ignored, and makes suggestions on what can be done to correct this. The working group for this paper met with the College Faculty of General Adult Psychiatry to discuss the direction of the paper. The HSE Early Intervention in Psychosis Clinical Programme, along with REFOCUS, Shine and General Adult Faculty of the College, plan to run a day conference/seminar to open up discussion on family involvement and how it can be enabled. This project is ongoing.

Psychiatric Diagnosis Project

The committee discussed writing a paper or perspective on psychiatric diagnosis, in particular to question the robustness of diagnoses, the length of time a diagnosis is valid for, diagnosis review and also whether there should be a mechanism to formally state a person no longer has a diagnosis. The committee formed a working group to work on this project which is ongoing.

Monetary Impact of Mental Illness

A subcommittee was formed to examine the monetary impact of living with a mental illness or caring for someone with a mental illness. The aim of the project is to build awareness amongst psychiatrists of how having a mental illness can affect one's ability to access or maintain employment, housing and income. It was decided to hold a half day workshop for College members and trainees with key stakeholders and users of the services. The aims of the workshop are that delegates will leave with achievable immediate steps they could take back at their service and also the possible development of an information leaflet for members. This project is ongoing.



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For some, being given a psychiatric diagnosis can cause difficulties in their place of employment and when searching for employment. Those who need support slip through the cracks due to a lack of resources and support.

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REFOCUS PAPERS AND PROJECTS (CONT'D)

Review of 5 years of REFOCUS Minutes

Christine McCabe completed a summation of all the minutes from REFOCUS meetings since the committee's inception, and compiled a list of the main achievements of REFOCUS to date. From this the committee discussed their future aims and how they can be best achieved.

Brainstorming Session

The Committee dedicated the December meeting to review their achievements, structure and future activities. In order to do this the committee broke into three small groups to brainstorm a series of questions. Once the groups had completed their discussions, the committee re-joined and presented their feedback.

Service users who speak out are constantly challenging stereotypes of people with mental illness; by being outspoken they are doing the opposite of what one would expect of someone with mental health difficulties (e.g. marginalised, withdrawn, quiet).

Those with a mental illness cannot show anger, sadness or elation, there is an inability to freely express normal human emotions for fear of coming across as being unwell or the assumption that these emotions are due to the mental illness.

REFOCUS INVOLVEMENT IN COLLEGE ACTIVITIES

REFOCUS members have been involved in a number of College events and activities throughout the year:

Oireachtas Masterclass Feedback

Following an invitation from the Ceann Comhairle two private sessions were held in the Dail with Oireachtas members to educate them on mental illness, mental health, treatment, and suicide. Psychiatrist members of the College presented on various topics followed by table discussion and Q&A which REFOCUS members were part of.

Advisory Board meeting with REFOCUS

Following an invitation from the College Advisory Board, five members of REFOCUS met with them to discuss the work of REFOCUS. The board, appointed by the College Council, is made up of influential stakeholders in society and meets with the College Officers to advise them on how to progress the aims of the College and its members.

College Annual Conferences

In April, Rick Rossiter and Christine McCabe attended the College Annual Spring Conference in the Sheraton Hotel in Athlone which was entitled 'Advancing Understanding of Mental Illness'. In November, Laura Louise Condell and Diarmuid Ring attended the College Annual Winter Conference in the Brehon Hotel/INEC, Killarney, which was themed 'From the Biome to Bipolar'. At both conferences REFOCUS members hosted a REFOCUS information stand which provided an excellent opportunity for committee members to speak to psychiatrists about REFOCUS papers, reports, and leaflets, and informed delegates why and how REFOCUS could be of interest and help to them professionally.

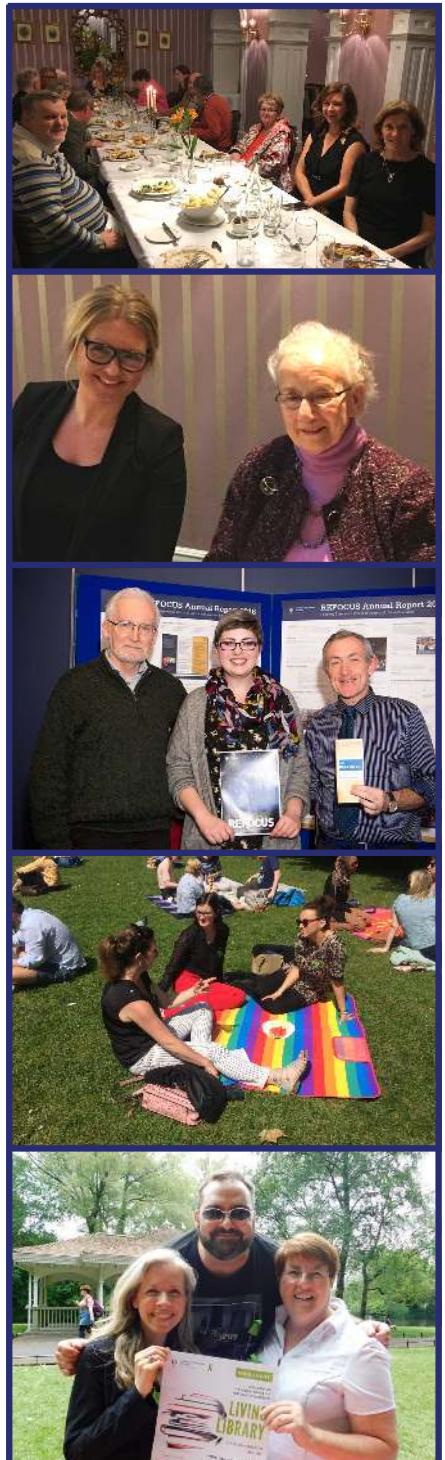


The most powerful way to connect is hearing peoples lived experiences.



Green Ribbon Month (May) – 'Living Library'

Following its hugely successful launch in 2015, 2018 saw the fourth annual event for Green Ribbon month with See Change. The College ran a new event, the 'Living Library', a library that comes to life in the outdoors. Members of the public and medical professions could 'read' human books featuring real experiences related to mental illness and recovery. REFOCUS members Louisa Corr and Rick Rossiter acted as 'books' for the event in Stephen's Green and spoke of their experience of mental illness and caring for a family member.



Photos from top - bottom:

1. REFOCUS meet with the College Advisory Board, April 2018
2. Dr Marie Oppeboen meets Catherine McGuinness of the College Advisory Board
3. Prof Anthony McCarthy with College REFOCUS members Laura Louise Condell & Diarmuid Ring at the Winter Conference in Killarney
4. Louisa Corr takes part in the 'Living Library' as part of Green Ribbon month, May 2018
5. Dr Sarah O'Dwyer, Mr Rick Rossiter (REFOCUS), Dr Miriam Kennedy (EAP Director) at the Living Library

REFOCUS INVOLVEMENT IN COLLEGE ACTIVITIES (CONT'D)

Induction Programme for Foundation Year Trainees:

In August the College ran its first weeklong induction training for foundation year trainees. Julie Healy and Rick Rossiter presented a plenary session on communication skills facilitated by Dr Verena Keane. It was well received by the trainees who gave the following feedback:

'The journey is what is important, what is valuable. Everyone starts at a different place on the path and no one knows where they will get to by the end of their time. People have different unknown beginnings and endings, but it is the journey where we meet and connect.'

'Julie's talk was fascinating. It's good to be reminded of how far we have come in terms of stigma and attitudes towards mental ill health.'

'I learned that taking care of carers' mental health and acknowledging the importance of family members are crucial.'

'I found it useful to learn how REFOCUS collaborates with the College to improve services through providing insight and an understanding of personal experience.'

On the last day of the programme Julie, Ciara Gillespie, and Rick co-facilitated workshops on communication skills.

“ Learning about the psychiatrist/professional point of view and experiences of professionals has created a deeper understanding of the mental health services. ”

Annual Spike Milligan Public Speaking Competition for Medical Students

Julie Cleere sat on the judging panel at the annual Spike Milligan Public Speaking Competition in November, where teams of two from the medical schools in UL, UCD, NUIG, TCD, RCSI, UCC & QUB spoke on the topic: 'Mental Illness: Everybody's Business, Nobody's Child'. Following some tough competition and debate medical students Ashlyn Fong and Orla Power from UL won the competition.

Meeting with Jim Daly TD, Minister for Mental Health and Older People:

Christine McCabe attended a College meeting with Minister Daly to discuss the idea of telepsychiatry which the Minister hopes to implement.

Pride Month - Mental health needs of LGBTQIA+ people:

During Pride Month, June, Laura Louise Condell, who is also the coordinator of the Dublin Lesbian Line which focuses on supporting women of the LGBT+ community, recorded a podcast interview on mental illness, mental health, and being part of the LGBT community. This was posted on the College blog and circulated to College members via eNewsletter



Photos from left - right:

1. Rick Rossiter (REFOCUS) cofacilitating a communications workshop at the Foundation Year Induction programme 2018
2. Julie Cleere with the winners of the Spike Milligan Public Speaking Competition 2018
(l-r back row: Dr David Weir, Dr John Hillery, Prof Anthony McCarthy, Ms Julie Cleere, front row: UL winners Orla Power and Ashlyn Fong)

REFOCUS INVOLVEMENT WITH POSTGRADUATE TRAINING

REFOCUS saw great developments in 2018 with ever increasing engagement with the Postgraduate Training Committee (PTC) and the Trainee Committee.

NCHD Conference 'Mental Health to Mental Illness - the role of the Psychiatrist in the 21st Century':

George Bridges and Anne Jeffers presented a plenary session entitled 'Forgotten voices in the conversation on mental health' at the 2018 NCHD Conference, run annually by the Trainee Committee. George spoke about the media portrayal of schizophrenia as well as his own experiences of stigma in the workplace and elsewhere. The talk gave a very powerful message that a person with schizophrenia can live a fulfilled life and that the psychiatrists and the team need to build up a trusting relationship with the individual between episodes of illness. There was great respect in the room and lots of questions and comments from the 120 delegates.

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The talk at the NCHD conference gave a very powerful message that a person with schizophrenia can live a fulfilled life.
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Summer School

The Trainee Committee runs Summer Schools in universities each year with the aim of encouraging medical students to begin considering psychiatry as their speciality.

Julie Healy and Laura Louise Condell delivered a talk on their own experiences of mental health difficulties, recovery, and the importance of family in aiding recovery.

These presentations were very well received with many students stating that the REFOCUS presentation was the highlight of the day, and praised the inclusion of someone with experience of the services.

Think Tank: Trainee Committee Quarterly eNewsletter:

Rick Rossiter continued his role as REFOCUS representative on the Trainee Committee's newsletter working group which writes and compiles their quarterly publication, Think Tank. Rick wrote a number of pieces for Think Tank including a perspective on how social media can be detrimental to real-world communication, and another piece on his personal journey of acceptance by others and of himself.

Inclusion in Accreditation Visits:

REFOCUS members were formally invited to join site inspection teams for accreditation of training by PTC. It is important that the trainees are aware of the central role those who use the services and their family members have in ensuring the training is fit for purpose. Anne Jeffers presented on the accreditation visits and their importance for ensuring trainees receive high quality training, and improving training and standards. The committee looks forward to receiving training on the accreditation process and joining College members onsite inspection visits.



Laura Louise Condell, Julie Healy,
Christine McCabe at the Summer School 2018

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This process is very important to ensure the College retains trainees, supports them, and produces the best trainees possible.
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CONCLUSION

2018 has been a very successful and productive year for REFOCUS. The group has continued to represent the College at external events. The committee would like to thank Kevin Jones and Ciara Gillespie, who stepped down from the committee this year, for their hard work and dedication to REFOCUS. It is also important also to recognise the contribution of Andrea Ryder, Mary Hayes, and Jennifer Farrell, key members of the College team who kept the group running as well as to recognise the College Director of Communications & Public Education, Dr Miriam Kennedy, for all of her support.

REFOCUS would like to thank and acknowledge the College Management Committee and Council for their continuing support for and belief in REFOCUS and their aims.

Finally, we must also thank Dr Anne Jeffers for her commitment to REFOCUS since its inception. Without her tireless conviction, there would be no REFOCUS to report on.

REFOCUS MEMBERS 2018

Dr Anne Jeffers (Joint Chair), Christine McCabe (Joint Chair), Kara Madden, Angela Dooley, Jeannine Webster, Laura Louise Condell, Diarmaid Ring, Julie Healy, Kevin Jones, Louisa Corr, Rick Rossiter, Tony Blackmore, George Bridges, Julie Cleere, Ciara Gillespie, Brian McNulty, Eileen McCluskey, Dr Clodagh Rushe, Dr Verena Keane, Dr William Flannery, Dr Marina Bowe, Dr Mia McLaughlin, Dr Marie Oppeboen, Dr Caoimhe Clarke, Dr Tiago De Castro Gomes.

Andrea Ryder (External Affairs and Policy Manager), Mary Hayes (Communications and Policy Officer), Jennifer Farrell (Communications Assistant)



College of Psychiatrists of Ireland

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