



Reaching Family Members in Large Numbers – Using the internet as a tool to enhance conversations with family members.

Ed Sipler - Health Development Specialist, South Eastern Health and Social Care Trust, Northern Ireland, UK.

Ed.sipler@setrust.hscni.net



Copyright APNINE 2021

What is the experience
of family members ?

Project 1: How affected family members (AFMs) can be reached effectively in larger numbers around the world

17 AFINet members from 13 countries responded and engaged in exchanges



Copyright AFINet 2021

To begin the discussion the question was put to members of AFINet, “What do you think it means to reach family members?”

- ⌚ Are we helping AFM’s realise they are not alone and what they struggle with is common to that experience?
- ⌚ Are we helping AFM’s come to see they deserve support in their own right?
- ⌚ Are we developing an understanding of what the barriers are to AFM’s seeking support, and how best to overcome these barriers?
- ⌚ Are we clarifying/improving our ability to communicate to AFM’s the potential benefits of them seeking support?
- ⌚ Are we clarifying whether help is available in each country and, if so, how to access the support that is available? Is that support for adults and children/young people?
- ⌚ Is there something else all together?

Views received
said yes to all the
questions
previously
mentioned and
added.....

Other views saw what it means to reach family members as a more complex question considering:

- ⌚ The relationship of the family member and the person with the alcohol, other drug or gambling problem can add to that complexity. Parents, spouses, adult children, grandparents may look at their situation somewhat differently. Dependent children add to this complexity if there is a child protection aspect.
- ⌚ Gender may play a part considering roles in the family and seeing help seeking as legitimate.
- ⌚ Cultural differences could be significant.

Core to family support, according to one responder on behalf of a focus group is helping family members realise they are not alone and what they struggle with is common with other people in similar situations.

- *“Without this understanding families remain isolated and stuck without hope or motivation to move forward”.*
- However it was also suggested that family members only come to this realisation – and deserving support in their own right AFTER they engage in support, i.e. it is not a motivation for getting involved. At whatever stage it happens, the mutual aspect is seen as fundamental to family support:
- *“Sharing experience is invaluable, reduces the misery and reassures us we are not mad or bad!”*



Disadvantages of ways tried to reach family members

Common disadvantages cited:

- Support is “hard to sell” both to patient and AFM.
- Despite extensive advertising services are under utilized.
- Posters and leaflets don’t often result in an uptake of engagement.
- Events scheduled get far lower turnout than anticipated .
- Use of the media does not guarantee editorial control.
- Short term, time limited funding means interventions and initiatives are of short duration.

Why don't people come forward for support is a universal question

What was identified as barriers in responses received during this stage of the project included:

- ⌚ Stigma, shame, embarrassment and cultures of blame remain significant barriers.
- ⌚ Many AFM's do not see the need for their own support as their main goal. A priority is to support the substance abuser.
- ⌚ Where the person with the alcohol, other drug or gambling problem is in the recovery journey will have an impact. With the family member sober, many AFM's don't see the need for help for themselves as the crisis has passed.
- ⌚ The opposite can be a factor. If treatment doesn't go well for the misuser, this can impact AFM's reaching out in their own right.
- ⌚ The situation can become **normalised** to the point that hope has been lost and families can't imagine another reality.
- ⌚ AFM's just feel "weary and worn out."
- ⌚ The benefits of support are unknown and AFM's only value the support once they have received it.
- ⌚ The accessibility and visibility of support available to AFM's is a huge issue with choice regarding the type of support limited.

.



The last point was a consistent theme from respondents.

Availability and consistency of support for AFM's varies greatly world wide and even when it does, it does not have a very visible profile.



Are we missing something?

- In a focus group conducted by the ‘Scottish Families Affected by Alcohol & Drugs’, one of the practitioners suggested a parallel with a **marketing model**, from ‘Attention to Interest to Desire to Action (AIDA)’.
- This involves the family member moving through cognitive (thinking) and affective (feeling) stages to behaviour (doing).
- ‘Reach’ as suggested through our original question “what does it mean to reach family members” may start with the ‘Attention’ stage and we must recognise that this is *“probably the most difficult as many family members are focusing on support for their relative and general unawareness of support for families in their own right”*
- This respondent noted we must be aware there are several steps between ‘Attention’ and ‘Action’ and we need to be mindful of and responsive to the barriers to progression through these.
- For example, even where family members are aware of available support, our experience is that they often don’t reach out for support services until a crisis point.

A large, light blue puzzle piece is shown against a bright yellow background. The piece is positioned on the left side of the frame, with its top and right edges visible. The piece has several interlocking shapes, including a semi-circular notch at the top and a semi-circular bump at the bottom. The background is a solid, vibrant yellow.

I know I have paid too much attention to the first piece

Attention

The family member becomes aware of their own needs for family support



Interest

What are the benefits to the family member of family support and how does it fit with their situation



Desire

The family member develops a favourable disposition towards family support



Action

The family member engages with/accesses family support.

Ways of
connecting
with family
members
way varied

Promoting a model of practice

Developing and delivering Interventions

Provision of written material

Training and research

Making contact and engaging family members

Screening

Use of TV, mutable means to communicate

Ideas you have wanted to try or have seen in other areas of work

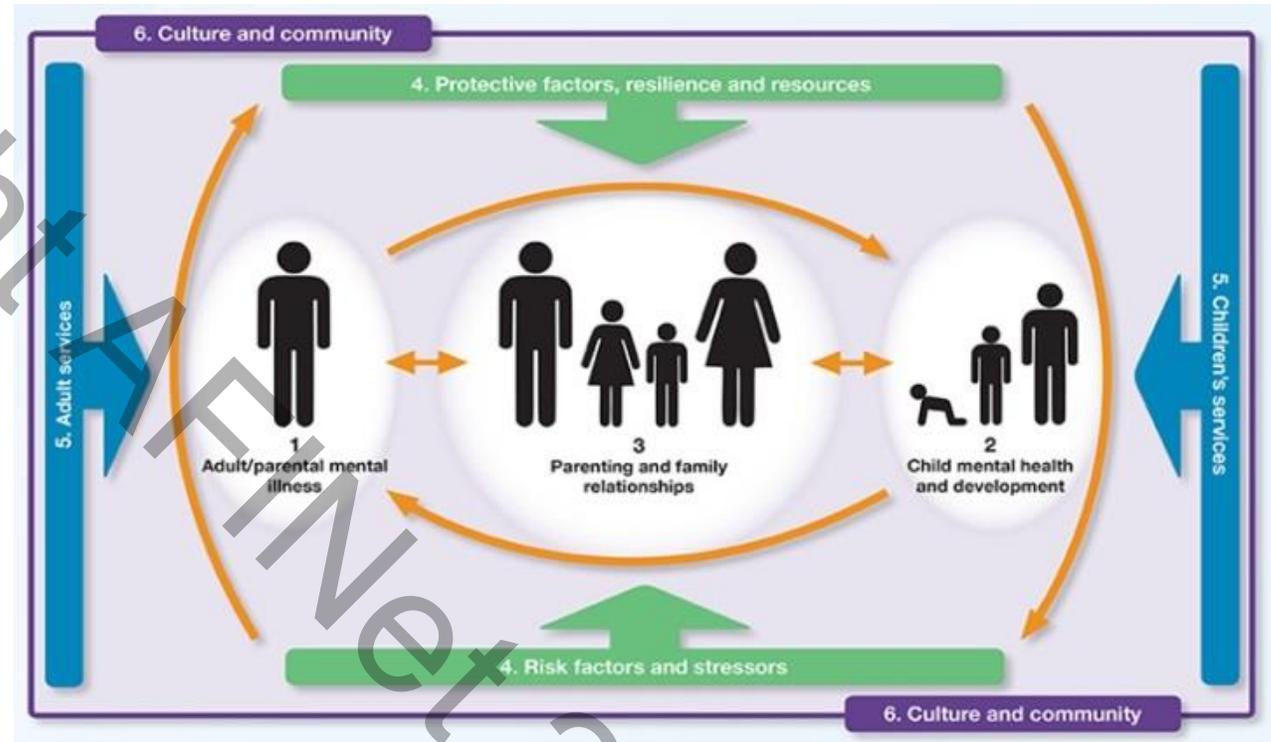
Promoting a model of practice

The Family Model is a useful conceptual framework to consider the needs of family members of someone with mental health difficulties.

www.thefamilymodel.com

They also developed open access internet based training and resources to enhance manager and clinician family focused practice.

What may appear highly effective is its simple use of a pictorial overview of the model.



A good number of responses talked about developing services and delivering interventions

- In England: young person's alcohol and drug service have a family service and are currently delivering CRAFT (Community Reinforcement and Family Training)
- In Western Australia: A State-wide 24/7 Telephone service for Parent with an added option of speaking to a Parent Peer Volunteer (PPV) with lived experience of a child who has had difficulties with A & D Parent Peer Volunteers facilitate unstructured groups and more structured BE SMART through SMART Recovery Australia.
- In Germany: Training and promoting CRAFT (Community Reinforcement and Family Training) as a treatment offered in a counselling centre
- In the Republic of Indonesia an assessment for family's needs followed by psycho-education sessions about addiction, recovery and family counselling
- In Norway: Social Network Meetings to strengthening relational bonds and help substance user and AFM's to voice their situation and needs
- In Iran: Companion Method is family members or friends who support the addict in their treatment journey called companions,
- In The Republic of Ireland: Systematic training of practitioners and accredited trainers in the 5 Step Method to support family members across the country. This has resulted in the organisation delivering training, the Family Support Network, being completely self-sufficient in the method.
- In Northern Ireland: Commissioning alcohol and drug to deliver family support and were trained in delivering the 5 Step Method. This approach has not resulted in self-sufficiency, yet it was the first time the need for dedicated support for family support was recognised and commissioned.



Interventions
for young
people

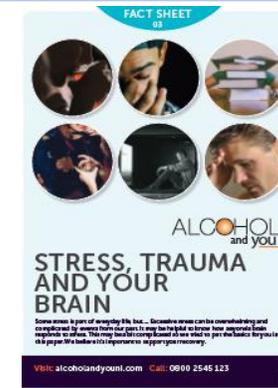
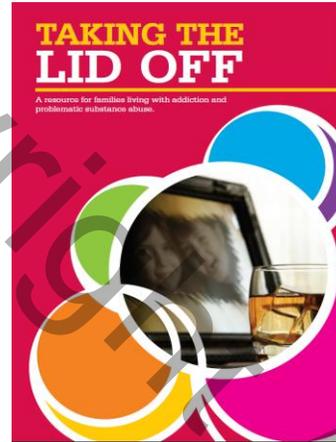
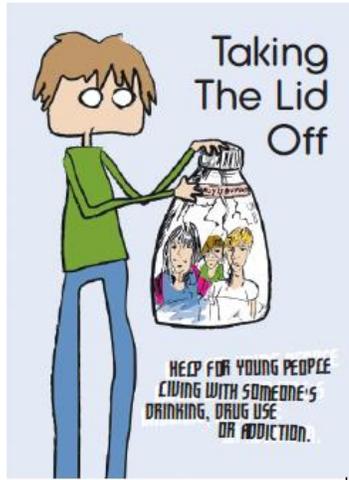
In Northern Ireland, adapting the adult 5 Step Method for young people 11- 18, tested the intervention and evaluated its impact.

-
(Sipler et al 2019)
<https://www.tandfonline.com/doi/full/10.1080/18387357.2019.1645607>

In England exploring a group recourse for children

In Germany: Developing and testing a modular group program called *Trampoline* for 8- to 12-year-old children from substance-abusing families.

Bröning et al.: Targeting children of substance-using parents with the community-based group intervention TRAMPOLINE: A randomised controlled trial - design, evaluation, recruitment issues. BMC Public Health 2012 12:223.

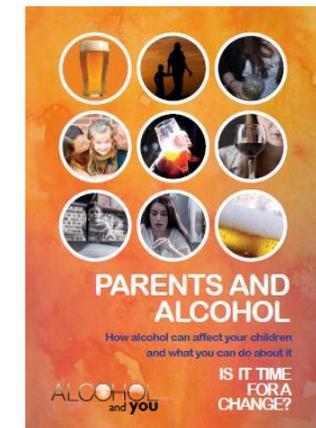


Informational resources

Much of my earlier work was talking and developing information for family members –

In Finland: Fragile published e.g. story books and work books on how to bring up the issue with child. Here's a link to "Little Fox has a Secret" (pdf)

https://lasinenlapsuus.fi/sites/default/files/pdf/little_fox_has_a_secret.pdf



Training

Scottish Families East Dunbartonshire Family support service have targeted GP practices to encourage support with AFM's experiencing stress or low mood.

In Nigeria: Drug Prevention Treatment and Care Sensitization Module have been developed to sensitize health care and law Enforcement practitioner on family issues.

In England training to school staff, of how to identify children who maybe in need of support and equipping them to be able to have initial conversations with parents.

In Northern Ireland the Steps to Cope created *Understanding and Responding to Hidden Harm: A Guide for Educational Professionals* is aimed at teachers

Lets not miss the massive work undertaken to put the 5-Step Method training on line





Research

- In the USA: interviewing 10 family members for a pilot study was a precursor to a dissertation project introducing the 5 Step Method.
- In England: Capture and use narrative analysis to analyse narrative experiences of adult siblings impacted by sibling substance misuse.
- In Nigeria: National household survey that include a section on harm to others as a result of someone else drug use (not excluding alcohol) This was the first National study on drug use for the country, to gather information on the harm experienced as a result of someone else drug use.

Making contact and engaging family members

- In Scotland: Scottish Families Affected by Alcohol and Drugs run a range of events that are not related to substance misuse but a range of engaging activities: flower arranging, art therapy, yoga etc. They use the media to raise awareness aims at challenging some of the negative attitudes, stigma and stereotypes around addiction.
- Family Addiction Support Service in Glasgow run holistic therapies for family members as an attempt to engage family members who may not come out for traditional support.
- A range of other groups in Scotland would run awareness raising events but an interesting twist on this would be Connecting Family Events. While not earmarking AFM's they promote fun, friendship and connecting to the community.
- Scottish Families – Family storytelling programme. Family members tell their story through film, audio and the written word. This creates an authentic and informed perspective that resonates with other family members.
www.familiesoutside.org.uk/family-stories/

Screening – Use of TV – multi angel approaches

- In Germany - Systematic Screening in primary care and motivating GPs and other practitioners to refer AFM's to treatment.
- Also in Germany providing a chat after a discussion on “co-dependency” in a TV-show resulted in 600 AFM's requesting help within one hour of the program.
- In the Republic of Ireland a nationality televised TV program focused on the experience of family members with support available communicated.

In Italy: A focused communication plan to convey the concept that the pathological gambler's family member can call and request an appointment for himself/herself, regardless of the fact his/her relative is AVAILABLE OR NOT to attend.

The communication campaign is multichannel: cards, billboards, place mats for canteens, website, social media, radio, etc. Periodic press releases are issued (at least two or three each year, coinciding with various initiatives carried out by the association).

The power of
the internet and
social media



The power of the internet

The reach of the internet- Fragile Children

7,862,137 views (2012) on Monsters

875221 On Orphanage (2014)



Media campaigns- Not relying on one method

In Germany a website www.kidkit.de, for children and adolescents in risky environments has flyers, short films, and songs presented on YouTube. Also, an interactive map presents local help services for affected children.

In Finland: Fragile Childhood is reaching out to young people via their web service Shadow World and social media. (Instagram, Facebook and Snap-chat).

My own use of You Tube
has reached 10K views in
a year – at 0 cost

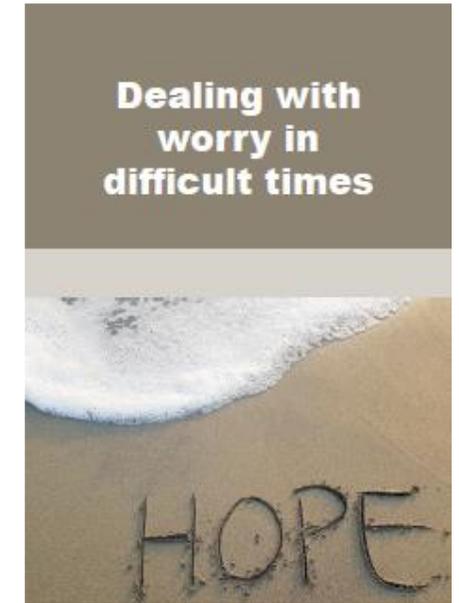
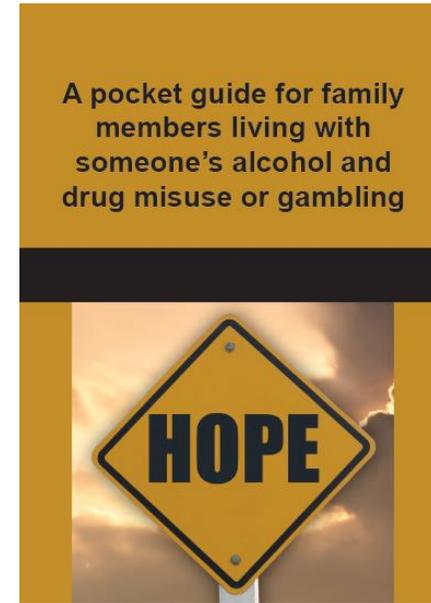
I love EOE in using information

Explore, Offer, Explore

That we talk about in Step 2 in the 5-Step
Method and was borrowed from MI

What an effective way to start a
conversation

Find them through searching Ed Sipler on
You Tube



Way forward-creativity and resources and sharing

- Need for practitioners to be trained to deliver services specific evidence based interventions for family members
- Residential breaks for AFM's
- Pay an agency to stock GP practices with leaflets to promote their services.
- Theme days for AFM`s with information during treatment
- Establish obligatory networking between institutions to build collaboration
- Online-offers might be a helpful way to reach more FMAs
- Provision of manageable strategies is an important attractor for FMAs
- E- Health is a large and a growing area and there is a lot to learn from how others are using it.
- More use of broadcast media to illustrate the AFM experience followed by where to find further information or help.
- A drama performance loosely based on research, touring around reinvent locations in which the AFM experience figures prominently, with discussion time and information following each performance.

Going back to what Jim said in March

Family members have:

no name

no collective voice or
identity

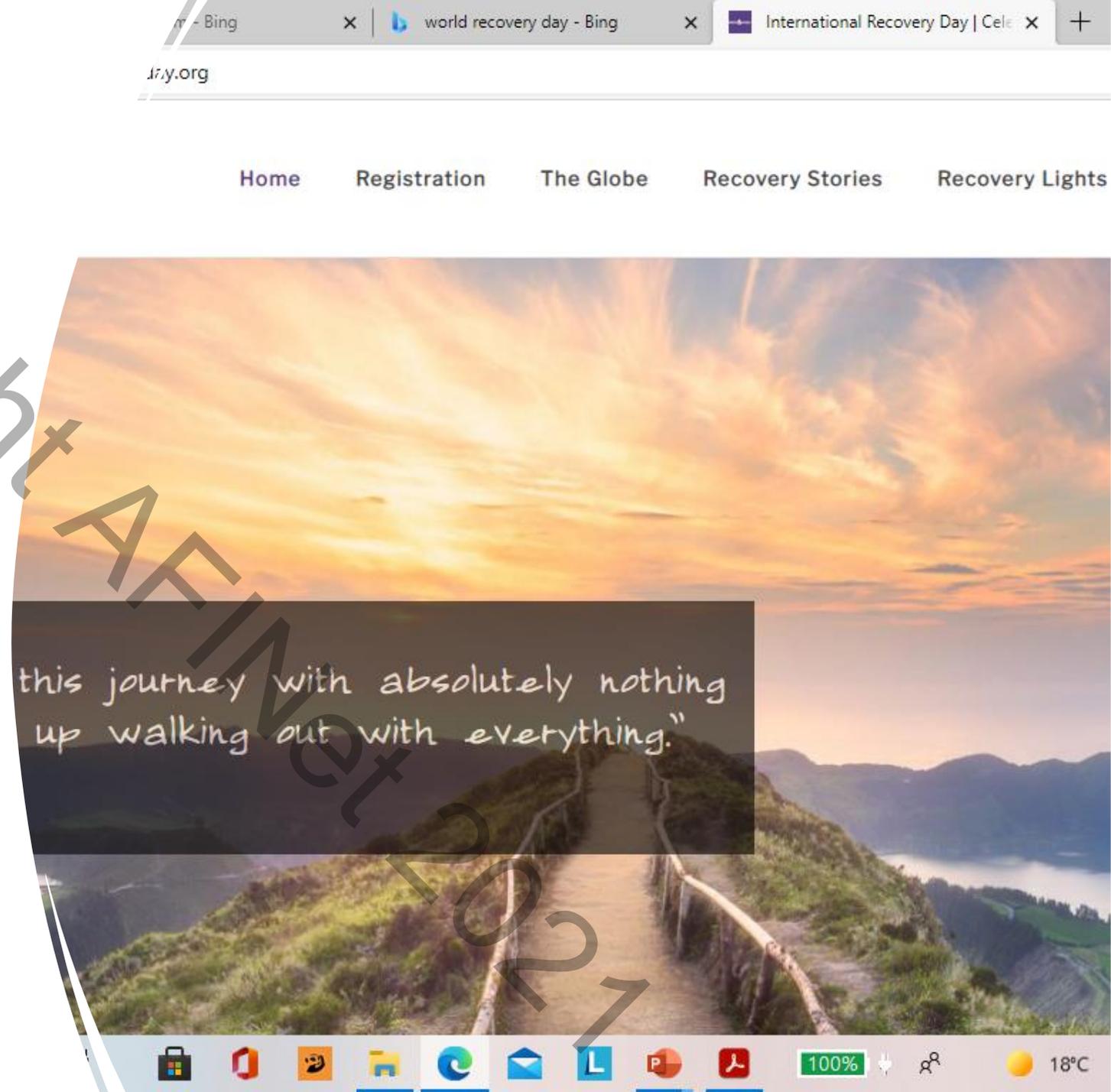
A lot could be learned how awareness days have raised the profile of other pertinent issues. In the UK World Mental Health day and World Suicide Day are prominent days in calendar and creates a range of activity. A suggestion is that a day marking the needs of AFM's be developed world wide.

International Recovery Day is a free online event to be globally launched on September 30, 2021

Founded by John Winslow in 2019, International Recovery Day, Inc. is dedicated to promoting all pathways of recovery from addiction worldwide and educating the public about the value of addiction recovery.

Overarching goal is to globally connect recovering individuals, families, and communities in order to provide worldwide hope to overcome addiction.

International Recovery Day connects the dots between all folks in recovery ~ from all recovery pathways ~ all around the globe ~ all in one day: September 30th.



Themes of what these efforts were attempting to achieve

- Build on the support available to ADF's
- Challenging negative attitudes, stigma and stereotypes people often have around addiction. (Who heard the Wisdom of Trauma?)
- To attract AFM's who may be reticent about reaching out for support and without connection to treatment or self-help systems.
- Increase knowledge of the experiences of AFM's.
- To empower AFM's to voice their situation and needs
- To establish a safe open room for talking and listening about important and difficult themes
- Skill up practitioners who directly working with drug users to begin to offer support to family members
- Develop interventions for children and young people where there is a clear lack of evaluated evidence based interventions
- The Parent and Family Drug Support Line emerged when parents wanted to speak to other parents experience similar challenges as a result of an audit of family Inclusive practice by the Drug and Alcohol Office. This example demonstrated how policy influences long term practice as the Parent and Family Drug Support Line has been running for nearly 20 years

What is most encouraging is when:

PRACTICE IS EMBEDDED AND SUPPORTED THROUGH NOTIONAL POLICY (AFINET PROJECT 2)

THE SKILLS SET OF THE WORKFORCE IS STRENGTHENED (AFINET PROJECT 3)

ORGANISATIONS WITH A DEDICATED FOCUS TO SUPPORT AFM'S SEEM EFFECTIVE IN ESTABLISHING LONG TERM SELF-SUFFICIENT MEANS TO SUPPORT AFM'S

EQUALLY ENCOURAGING ARE NEW AND ADDITIONAL WAYS OF REACHING AFM'S COMMUNICATED THROUGH THE AFINET NEWSLETTERS.

As one family member who availed of support in Northern Ireland said,

- *“It took me a long time to realize I needed help for myself. I was so preoccupied in” fixing” my family member that I ignored my needs.*
- *I saw posters and leaflets continually that kept saying there was support there for me but the message was not heard for a long, long time.*
- *One day the penny dropped and I’m so glad it did.*
- *My message for you is keep getting your message out there in every way you can – drip, drip, drip because you never know when that message will hit home.”*

Thanks for joining me today:
ed.sipler@setrust.hscni.net

So taking all this in
What did you hear
today that you
found helpful?

Now the big question- **WHAT
ARE YOU GOING TO DO
WITH IT?**

