

# Open Dialogue Mental Health Pathway Evaluation: Executive Summary



This report was prepared by the National Suicide Research Foundation (NSRF) on behalf of the Health Service Executive who commissioned the NSRF to conduct an independent evaluation of the Open Dialogue initiative in Cork Kerry Community Healthcare. The project was led by Professor Ella Arensman, Ms Eileen Williamson, Nora Conway and Carolyn Holland, supported by a Working Group overseeing the research project.

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## List of Abbreviations

- TAU- Treatment as Usual
- OD -Open Dialogue
- MHP’S -Mental Health Professionals
- MHS- Mental Health Services
- HSE -Heath Service Executive
- WHO- World Health Organization

## Introduction

Mental health care and recovery is complex and requires both a holistic and individualised approach to fully understand and meet the needs of people who are affected by a mental disorder. While there has been a seismic shift in how mental care is organised and delivered in Ireland and internationally over the past two decades there are still gaps in how people with enduring mental health needs are treated and cared for. People living with a severe mental illness tend to experience greater health inequalities, as well as life outcomes and opportunities in comparison to the general population. The impact of mental health is far reaching, not only for the individual, their families but also for society at large with significant psychological and economic impacts.


The delivery of evidence-based interventions is paramount to address the intricate needs of the people who live with an enduring mental illness. Of primary importance is to ensure timely and effective access to services, as well as treatment and care that is both therapeutic and supportive to ensure that people who experience mental illness can reclaim or recover meaningful lives. There is a growing recognition that mental health pathways should be inclusive and involve the service user and their support in every step of the care journey. The HSE outlines their commitment and vision to mental health recovery in their policy document National Framework for Recovery, (HSE 2018-2020) and Department of Health policy document Sharing the Vision (2020; 2021); which encompasses principles of self-determination and personalised care. The World Health Organisation (WHO) has called upon policy makers and mental health services to work from a human rights based approach, to ensure that the people who experience mental illness receive the clinical care they deserve, that optimises recovery and supports people to live meaningful lives within their community (World Health Organization, 2019).

This report provides an overview of the main findings of the Open Dialogue Mental Health Pathway Evaluation, undertaken by the National Suicide Research Foundation on behalf of the Health Service Executive. The main aim of the evaluation was to explore key stakeholders' perspectives of Open Dialogue as a clinical intervention and recovery model of healthcare. The report gathered feedback from the direct experiences of individuals who have accessed West Cork Mental Health Services and those involved in delivering clinical care. Soliciting their perspectives is integral to identify how mental health services can best support and maximise personal recovery opportunities. The recommendations reflect the changes that are required for clinical practice if they are to truly transform how people with an enduring mental illness are cared and treated.

## Background

Open Dialogue (OD) is considered both as a therapeutic approach to support people dealing with an acute mental health crisis and a way of organising clinical care in response to the mental health crisis. As a therapeutic approach, OD places the person at the centre of their recovery, mirroring the values and principles of a recovery-oriented model of healthcare. Critical to OD delivery, is client engagement and empowerment, inclusion of a support network, as is a continuity of care across services for the person in crisis. There is a strong emphasis on democratic partnership, and on dialogical practice, within network meetings (Lakeman, 2014; Seikkula & Arnkil, 2006).

## Evidence

-  First Developed in Western Lapland in the 1980s to address high rates of hospitalization for schizophrenia, and psychosis.

- ✚ Evidence-based studies within Western Lapland have shown to be effective in treating and supporting those who experience first episode psychosis. The Western Lapland group collected data on their outcomes with non-affective psychosis that compare favourably to an historical control group – at 5 years follow up over 80% were back at school or work and not taking anti-psychotics while only 14% remained in receipt of disability benefits (Seikkula et al., 2006).
- ✚ Open Dialogue has since been implemented internationally including in the US, Australia, Germany, Italy and the UK (currently undergoing an RCT) with some initial promising results (Gordon et al, 2016; Buus et al, 2017; Schütze, 2015; Razzaque & Wood, 2015).

### Context

Open Dialogue (OD) was first introduced as a clinical care pathway to West Cork Mental Health Service in 2012 to respond to the needs of the people who experience severe and enduring mental illness. Broadly because of the clinical drive and community healthcare's ethos to improve the quality of care for people living with a chronic or enduring mental illness; investment was awarded in 2012 and 2014 to enable staff to receive training in Open Dialogue principles and techniques through the Genio Disability & Mental Health Grant. Since then, Open Dialogue has been co-opted as an integrated and needs adapted approach to treat and support people who experience acute mental distress.

### Aims

The current study seeks to evaluate both the impact and implementation of OD within the West Cork Adult Mental Health Service, from multiple points, including clients' experiences of their care process, that of their social network, and professional team in comparison to treatment as usual (TAU).

### Rationale

While existing research has provided information on clinical outcomes and implementation challenges, in other countries, there is still a gap in research with regards to how OD is experienced from an Irish perspective. By evaluating the experience of the mental health professionals, the service user and that of their family/ support worker we aimed to obtain real insight into how Open Dialogue as a recovery-oriented model is experienced. The aims of the research project were to evaluate the effectiveness of OD as a clinical model of care, in terms of treatment and outcomes in comparison to TAU.

### Methodology

The study adopted a mixed-methods approach involving both quantitative and qualitative methods of data collection and analysis and comprised of three distinct phases of data collection over an 8-month period from September 2021 to March 2022.

- ✚ Quantitative Phase 1 of the evaluation comprised of an online questionnaire inviting mental health professionals (n=7) to share their experience experiences of using Open Dialogue as a clinical care model within the HSE Adult Mental Health Service.
- ✚ Quantitative Phase 2 of the evaluation involved gathering quantitative data in relation to the service users (n=12) and that that of their family/ support worker (n=2) through an online

questionnaire. The questionnaire included sociodemographic items including age, gender, diagnoses and duration of treatment. Standardised validated instruments of involvement, decision –making, recovery and quality of life were used to gather the data.

### Phase 3

The third phase of the evaluation consisted of a **focus** group and telephone interviews with ‘service users and their family / support network (n=15) who had availed of OD and/or TAU as part of their treatment and care whilst attending the West Cork Mental Service. Interviews were designed to elicit rich descriptions and gauge their subjective feelings and perceptions of OD as a clinical care model in comparison to TAU.

### Ethical Approval

Ethics Approval Ethical permission sought and granted by Clinical Research Ethics Committee of the Cork Teaching Hospitals in August 2021.

### Results

The result of the study reveals that OD was well received by the majority of participants involved. Both quantitative and qualitative data yielded valuable insight into how service users and their support network and mental health professionals experienced Open Dialogue with the overarching experience being consistently positive. Service users and their family members identified key aspects of Open Dialogue which they felt were unique or different and were deemed to be central to their recovery. This includes access to the same clinical care experts, being treated with dignity and respect, and being actively involved in key decisions around their treatment. Quantitative analysis of the different standardised measures showed high rates of satisfaction with Open Dialogue in with respect to recovery orientation, therapeutic alliance and involvement in clinical decision making.

Mental health professionals reported the value of being able to work closely with their client and their family or support network, and reported the advantages of being able to work collaboratively with colleagues, and enjoyed the reflective space where a shared understanding was created. Four major themes were unearthed and include (1) relational aspects such as humanity and compassion, being treated as equal and with dignity and respect (2) network meetings as communicative and collaborative pathways; (3) network meetings as being the catalyst for change and (4) the challenges and barriers experienced within the mental health services and include subthemes that relate to access and permeability of services and lack of out of hours/crisis. TAU in comparison to OD was deemed to be more disempowering, as there was less engagement and involvement by service users and their support network in key decisions related to treatment and well-being.

## Relational Aspects

### Humanity and Compassion

The majority of participants found that the OD network meetings were unique and different to what they would have experienced previously when engaging with other mental health services (MHS). Service users spoke of the intentionality of the mental health professionals to support them in every step of their recovery journey and attributed much of their recovery to the supportive and healing environment in which they were met. This is reflected by the quote from one of the service users' first impression of Open Dialogue:

*"Like I walked in and there it felt very safe and like it felt a place where you could be yourself. was no air or stigma,".*

Service users and their families spoke of the *grace and humanity* with which they were greeted at every network meeting which they felt was atypical of their previous encounters within the service. Service users were surprised by the level of care and attention that their OD team afforded them. One service user reflected:

*"They made it very clear that they cared about what I was going through."*

This was further echoed by a family member who commented on the therapeutic presence of the care team who were involved in treating her son.

*"Just the care and the gentleness, of her; the way she just expressed what she was feeling, on what she had heard and that was quite touching, you know, for me I couldn't say how my son felt about it, I am not sure but for me, I was touched by the care and the carefulness, and the quality of the listening and the reflections that were being made".*

Another service user spoke of their way of being: *"they were just so very supportive and so kind and gentle, even in their tone of voice you know. And if I wanted to cry I was able to cry, and if I didn't want to say anything, that was okay too".*

### Dignity and Respect

In addition, the service users and their families felt that within the network meetings, they were treated with dignity and respect, and felt that they were very much seen and heard by their care team. For one service user, he liked the fact that Open Dialogue was *"person-centred"* and that *"there is no hierarchy"* and also mentioned how *'natural'* the care team were. One participant in particular mentioned how nothing was *'pushed upon you'* and that she felt *"very much listened to"*.

In addition, service users and family members remarked on how interactive the network meetings were and welcomed the fact that they were able to set the agenda for the network meetings, giving them the space to raise issues or concerns without experiencing fear of being judged or criticized. One service user liked the fact that the network meetings were *"informal, like sitting down for a chat"* and was struck by the balance among the clinical team at the network meeting.

*"The balance was amazing as well, between themselves, there was humor used, you know and it was well-timed. All these things just made me feel more relaxed".*

Previous clinical encounters were juxtaposed to OD treatment meetings where service users highlighted how they were often treated with disregard, and overridden in the treatment room. One

participants spoke of a clinical encounter that lacked empathy or human connection which affected her treatment and recovery.

*“So I was brought into this psychiatrist, who basically just sat there ...and never really looked at me you know; barely looked at me and just start asking me all these questions and wrote it down in his notebook and I just found that there was just no feeling of care or compassion.”*

Another participant highlighted her frustration at not being seen beyond her diagnosis and only being offered medical intervention when she needed someone to talk to.

*“The first thing they tried to give me was antidepressants and sleeping tablets. You know it is just a quick fix. Treat the symptoms and not the cause. Yeah, that's the problem, isn't it?”*

Some of the service users spoke about the need for more training and understanding among all staff when supporting people who experience mental distress. One participant highlighted her frustration at being left wait in a corridor while being in an acute state of anxiety:

*“I found the waiting was very hard. An yeah I was just you know kind of up and down to the receptionist, asking just when could I get in and I didn't really feel any kind of compassion or comfort coming you know ... not even from the receptionist; there was more of a.. kind of sit down and wait kind of attitude”.*

### Autonomy

Participants remarked on how gratifying it felt to be included in decisions that affected their mental health and recovery, and that fed into their sense of self-worth. Service users who received TAU specifically spoke of the feelings of disempowerment they experienced as they were not considered or supported when key decisions concerning their mental health treatment were made. Service users highlighted how powerless they felt at times, struggling to make sense of what was going on and spoke of the immutable powers of men in white coats *“you don't know what they're saying and then you just get more panicked*. Open Dialogue by comparison gave the service users the opportunity to engage and challenge medical decisions which added to service users sense of empowerment. The network meetings were also perceived as beneficial in improving patient-doctor relationships, which in turn supported participants in being able to better advocate for themselves in relation to their medication. For some of the participants, this meant that they were able to either reduce or stop medication. This is juxtaposed by previous experiences in engaging with mental health services who felt that there was an over emphasis on prescribing medication and where they didn't appear to have a say in decisions around medication.

### Network meetings –an arena for communicative and collaboration

#### Shared Understanding

Open Dialogue network meetings were seen as a conversational space where mutual understanding was gained. Within the walls of the treatment room everyone was invited to share their thoughts and feelings, and talk about what is important to them. The mental health professionals spoke of the benefit of hearing all sides and the significance of the network meetings in establishing or enhancing communication. For the mental health professionals, the network meeting provides them with *“a wider lens to understand their clients”* and an opportunity *“to get to know the person and their network as well as their issues, as well as time for the person to get used to working with a team”*. All participants recognised the value of working with a consistent team and felt that it helped to create that sense of openness and transparency and reflected how it allowed for deeper reflection and connection.



*“Well I didn’t have to explain myself you know. It was just like starting a page of a book you know, I was able to go on from page to page with my life, and do you know what I mean”.*

Participants spoke of the emotional distress experienced when dealing with changes in personnel and having to rehash information in relation to their mental health. They felt that Open Dialogue, through the network meetings offered them a co-ordinated level of care. The interactional context of the network meetings encouraged participants to open up and be more free, and gave the opportunity for the silenced voice to be heard.

#### Enhanced Communication

Several of the participants spoke of the benefit of hearing other people’s perspectives and reflected how OD made it easier for them to express feelings that they were unable to express previously on their own.

*“I brought it up in the room it was a lot easier to talk about, so it was.*

*Maybe at home we couldn't talk, like I was going through a lot so maybe I felt like I couldn't talk to personally about it.”*

Furthermore, family members appreciated being invited into the network meetings, and felt that they gained a better understanding of their loved one’s illness whilst being present at the network meeting.

*“I liked being part of the conversation. It was good to hear what they were saying and to be invited to add maybe my perceptions of things or maybe my experiences and any concerns that were relative to me and to be able to say that with two witnesses as such. Ehm so I was appreciated that “.*

Relatives spoke of the agony of being on the periphery and being excluded from treatment meetings in traditional psychiatric settings. *“I really do think it's great you know rather than sitting at home panicking, you know what's happening in there.”* In the network meetings everyone was given a chance to interact and share their thoughts.

#### Digesting Reflections

Family members and service users commented on how they were given the time and space to digest what had been said in the room and remarked on how useful it was to hear the different perspectives which they deeply appreciated. The clinical team acknowledged the benefit of the reflective process as it tended to broaden perspectives, and encouraged new ways of thinking about self and others. The mental health professionals also highlighted how their role changed within Open Dialogue, and that they had greater freedom to express their feelings and share their thoughts. One member of the clinical team felt that *“relationships are more personal than in other ways of working”* and commented that they *“share more of myself than I would in a one to one setting”*. Professional staff also commented on how OD brought: *“new depth to the idea of being client centred. As a trainee recently said, I always said client centred, now I know what that actually means”*. In every instance we can we share with the client, we offer the client power over when and how often they need to be seen, we do notes collaboratively, we tune into the feelings in the meeting we are present and supportive at a time they need that."

Furthermore, the healthcare professionals spoke of the value of working alongside others and felt it gave them an opportunity to enhance their own skillset as a mental health professional.

*“I am very happy to work in this way. The implementation has challenged me to change my practice..... with a colleague present we can sit in the uncertain space for longer especially*

*with risk or big decisions or disclosures are present; this allows us to take time and not rush to fixing or shut down important insights or feelings.”*

The network meetings were deemed to be deeply insightful as they offered a reflective space where all voices were heard. Service users and their family members welcomed the mental health professionals sharing their thoughts and felt that it brought a greater level of understanding and meaning to the treatment room. While the reflections initially felt weird, the participants reported becoming more comfortable with them over time; perceiving them as being beneficial to the therapeutic process. For the mental health professionals, OD offered a different way of being with clients who experienced mental distress and favoured working in this way. The MHP’S spoke of the benefit of being able to share and express their own feelings, and not always having to wear the mantle of the expert. The challenge for the professional team was in allowing for uncertainty or in working with different skillsets and personnel. Whilst all mental health professionals found it deeply gratifying to work in this way, some did find it challenging.

*“I found it challenging to identify and manage the differences in working practices”.*

### Network Meetings – the catalyst for change

All of the participants mentioned how the network meetings had the potential to bring forth change as the network meetings emphasised dialogue and shifted focus toward growth and recovery. Service users specifically spoke of the intentionality of the professional team to support them in every aspect of their recovery journey and were impressed by the fact that their care team were interested in supporting them on many guises, and gave them hope for the future.

### Hope and Optimism

Network meetings were perceived to be imbued with a sense of hope and optimism and not just on symptom reduction. Participants spoke of the focus of the network meetings as being forward-looking and that the mental health team encouraged them to explore their interests, hobbies and any aspirations they may have. One participant reflected:

*“I did a fayre and one of them came in and they were so proud of me in doing it. Actually one came to support me, she came and she looked at my stall and bought something, just so that, you know it was supporting and then I came in and they were like how did it go. [...] You know it's just so friendly and I don't think without it, I would be here or be half as good as I am.”*

This was contrasted by service users experience of TAU, specifically in relation to their experience of psychiatry. The majority of participants felt that conversations were limited to symptom reduction, and all agreed that key decisions in relation to medication were made without them. Overall OD was experienced as positive, and offering a much needed alternative to treat people with a mental illness. Participants felt that network meetings should be a part of the standard treatment across all mental health services.

*“ All I would ask is ehm and I know the lead and the research lead, that all the staff would sit down and push this as far as you can, well of it saved me, I am pretty sure it has saved others”.*

Another service user expressed his desire for *“the hub we have in West Cork to be expanded, ... more funding that would be my wish”*. One mental health professional concluded that *“OD leaves me with a sense that the basic human rights are met from the get go. I love the 'nothing about you without you' and the 'seeing the person for who there are and where they are at' just fantastic.”*

## Challenges and Barriers Experienced

The participants were asked to share their feelings on any difficulties that had whilst attending OD clinics. Participants in general were extremely satisfied with OD despite their being some interruptions to service during COVID. The following issues and tensions reflect the participant's overall views and experiences of accessing mental health services with West Cork Mental Health Service.

### Permeability of Services

Most of the participants expressed their frustrations around access and permeability of services and spoke of the inadequacy of the healthcare system in supporting them through their mental health crisis. Several of the participants spoke of their frustration at not being able to access services in a timely fashion. One mother in particular commented on the fact that there “was a lot of white noise” when it comes to accessing support for a loved one going through a mental health crisis. She remarked how she had “knocked a lot on those doors and there is nothing behind those doors, that is very frightening”. Another patient felt that it “was such a long time before I could talk to someone.”

### Lack of Crisis Care

The participants highlighted the need for ‘24 Hour’ crisis care across mental health services. The majority of the participants felt that the mental health system need more funding and extra resources to ensure that mental health crisis teams exist out of hours and that emergency departments were not suitable for dealing with people in a mental health crisis.

### Dominance of the Medical Model

Service users equally expressed their frustrated at being prescribed psychotropic medication as the first or only alternative as opposed to other interventions.

*“When I attended my GP when I was going through quite bad depression, I was quite ill and all they wanted to do was give you antidepressants and that seems to be the same for pretty much for any (..) that just. Seems to be the first port of call to give you antidepressants. So it' took me a long time to actually get to see anybody to talk to and I would like that to have been a lot quicker.”*

## Conclusions

Overall, the findings of the evaluation show that Open Dialogue was well received by the service users, their families and mental health professionals involved in the study. All participants, but crucially service users expressed their satisfaction with engaging in OD as a therapeutic approach and felt that OD aligned with recovery-oriented values and principles.

Service users and their families spoke of the inherent difference of working with a team of professionals that seemed to truly care about their mental well-being and felt that compassion and humanity in which the network meetings were held was key to the recovery process. Of note was the

shared sense of mutuality that peer support workers brought to the table in sharing their lived experience of living and managing to move forward whilst experiencing mental health difficulties.

Furthermore, service users and their families linked their recovery to the use of shared decision-making. Participants spoke of the sense of empowerment as they were given the opportunity to become active partners, making key decisions in relation to their care and treatment. Equally, the interviewees mentioned the impact the network meetings had on their self-esteem, as it engendered feelings of control, mastery and self-confidence which allowed them to reengage with life and living.

All participants described the benefits of the reflective process and the role that the network leaders have in ensuring that all voices were heard in the room. The reflections and reflective process brought greater insight and helped the individuals to see things differently which supported them in their recovery. The network meetings whilst often emotionally charging were also seen as the catalyst that brought the change as people were able to discuss their thoughts and feelings without fear of being criticised or judged. This is consistent with previous research whereby Seikkula and Arnki (2013) refer to this as “respect of the otherness in the present moment”.

In addition, mental health professionals also acknowledged how OD supported them as professionals to work in a more open and transparent manner. Furthermore, MHP’S spoke of the benefits of working with and alongside others and felt that Open Dialogue offers a space for mental health professionals to sit with uncertainty and not always being the expert.

Collaborative care, as offered by OD would appear to address some of the shortfalls seen in the current healthcare system, however more research is required to upscale OD and assess its effectiveness as a clinical care model. The findings are consistent with previous research in the field of Open Dialogue which indicates that Open Dialogue allows for recovery-oriented, person-centred care.

This study demonstrates that OD has merit as a treatment approach and ought to be considered alongside other and existing treatment options within the West Cork Mental Health Services, with a view of upscaling OD for wider implementation in Ireland.

## Recommendations

- Overall, the findings from the evaluation demonstrate that OD has merit as a treatment approach and ought to be considered alongside other and existing treatment options within West Cork Mental Health Services with more training made available to staff across the service, to ensure that the underpinning of OD evolves across the service.
  
- Furthermore, the findings support the upscaling of OD across the Health Service Executive at national level, as it has the potential to improve the quality of life for individuals experiencing severe and enduring mental illness, as it seeks to support the person on a holistic and psychosocial level. OD demonstrates that increased well-being is possible despite living with an enduring mental illness and that recovery is based not just on treating the symptoms but on empowering people, enabling them to be autonomous and self-directed, in pursuing their goals and dreams whilst providing tailored care and treatment.
  
- Network meetings should be established as a part of routine clinical care, with family members being invited in to be part of the treatment and healing process. All participants spoke of the benefit of hearing different perspectives, where mutual understanding and reciprocity were experienced. Service users and their families valued having a more interactive experience in the network meetings in comparison to TAU. Participants in our study spoke of the sense of empowerment and agency as they were involved in key decisions in relation to their care and treatment. Furthermore, the interactional context of the network meetings engaged psychological processes that enhanced their learning, and mobilised individuals to see their inner strengths and resilience.
  
- Participants spoke of the need for the development of a single point of entry for crisis referrals and recognised the need for an out of hours' service to support people going through a crisis. Service users and family members spoke of their dissatisfaction at having to access mental health services through hospital emergency departments (ED's) describing it as wholly unacceptable and distressing, particularly when experiencing a mental health crisis.
  
- Furthermore, the findings of the study recognise that the dominant biomedical model of healthcare that currently exists within the HSE is inadequate to meet the complex needs of the individuals who present with an enduring mental illness and that a cultural shift is required across mental health services to ensure that services focus on the person through the lens of their whole life, and not just solely on symptom reduction.

## Strengths and Limitations

This is the first in-depth study in Ireland to explore and evaluate the tenets of Open Dialogue as a recovery model of healthcare pathway. The findings provide key insights into how Open Dialogue was experienced, by service users, their families and clinicians and serves as a marker in how mental health practices should be delivered.

Limitations of the study include being unable to involve all service users who that engaged in Open Dialogue between 2018 and present date, which was in part due to difficulty in recruitment, the lengthy periods of recurring lockdowns and participant profiles.

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