

Overview and Evaluation of the National Family Support Network 14th Annual Service of Commemoration and Hope

Our Children, Our Family.

*'It is not enough to say certain things just once. Some things need to be said and said until
they don't need to be said again'.*

Father Tim Wrenn, quoting Margaret Atwood, 2013.

Events like this show us how far we have come as a society, not to sweep people's lives under the carpet and ignore their families.

Minister of State for Primary Care, Alex White

I had a son on drugs for 15 years. I have to say the support group saved my life. The ceremony is so special it brings it home the people that have lost children have the support all around them. It's a circle of friends. A woman at this table buried her only daughter just before Christmas, that's why we all came - to support her.

Respondent, evaluation

It was only after the death of our young son Mark, 9 years ago, that we became very isolated. We found our local family support group and learned ways to take care of ourselves. On this day last year, we got a call to say another one of our sons had taken ill and was in hospital. Later that month sadly we lost another one of our sons. While we were devastated, we found a way to deal with it in a different way. We believe this is because of the amazing support we received from the staff and our friends in the family support network. What really helped us was that we started to attend the monthly bereavement group, just one month before our son died.

Participant, Service of Commemoration and Hope 2013

It's very important to me. It's very touching. Absolutely lovely. When I'm here, I'm on the same level as others.

Respondent, evaluation

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Part one

Summary of events: The 14th Service of Commemoration and Hope

Introduction

The 14th Annual Service of Commemoration and Hope was held in our Lady of Lourdes Church on Sean McDermott St, Dublin 1, on Friday the 1st of February 2013. Over the past 14 years, the ceremony has continued to provide support and to honour the memory of loved ones, promoting friendship and hope amongst those with a shared experience of losing loved ones through addiction related causes. In this time, it has grown from a collection of Dublin groups honouring loved ones lost and supporting surviving family members, to a congregation with representatives from family support groups across the country. In many ways, the growth of the commemoration has reflected the growth of the National Family Support Network and its affiliated Family support groups across the country, which now number 83 in total.

On the evening, the church was lit in purples, pinks and reds, highlighting its impressive roof and the many handmade quilts that hung from ceiling and wall. Each patch on every quilt represented a loved one that had passed away due to addiction related causes. Patches told stories of the pain and loss that these deaths had brought to families and communities across Ireland. As hundreds of people gathered in the church from around Ireland there was a respectful hush. The church was transformed into a place of comfort and solace for those wishing to remember and share their experiences with friends, families and those strangers who, while never meeting, understand their journey so well. As the entrance song started there were few seats left in the church.

Opening

*“There’s a road we’ve been travelling, lost so many on the way.
But the riches will be plenty for the price we have to pay”.*

The ceremony opened with the impressive gospel style singing of St. Mary’s Youth Club who performed *I know Where I’ve Been* from the musical *Hairspray*. This was followed by a dance performance by The Francesca Arkins Dance and Stage Academy. A large group of

children and teenagers dressed in white and danced and sang to Michael Jackson and Lionel Richie's 'We Are the World'.

Each performance received a warm and enthusiastic round of applause from the family and community members present in the church.

Welcome

Father Tim Wrenn warmly welcomed the crowd to the church and spoke about the theme 'Our Children Our Family'. He reminded the attendees to continue to love in the spirit of all who have gone before us, never forgotten.

Sadie Grace of the National Family Support Network (NFSN) welcomed all attendees on behalf of the National Family Support Network. In particular she acknowledged the attendance of Pdraig McLoughlin representing the Lord Mayor, Commandant Michael Tracey, John Twomey, Bishop Eamonn Walsh, Gordon Jeyes, the National Director of Child and Family Services, Minister Alex White and all other public representatives and religious representatives. She reserved the warmest welcome for the family members living with substance misuse on a daily basis, especially those who were there for the first time. She highlighted that the latest report from the National Drug Related Death Index which showed that over 575 people died from drug related causes in 2010, and that this figure is understood to be a conservative estimate.

Sadie informed the people present that the NFSN were aware of how upsetting the service can be and for that reason there were counsellors available if anyone needed one.

Sadie highlighted some of the work the NFSN have done over the last year and work for the coming year to support family members dealing with substance misuse issues:

- Establishment of a bereavement support group in the North Inner City.
- Establishment of a sibling support programme.
- Development and roll out of training on responding to intimidation.
- Training and roll out of the 5 Step Method, an evidence based model for families dealing with substance use issues.
- Running the Annual Work Conference in November, which saw 426 people in attendance and was a great success.

Sadie noted a cause for celebration in the huge growth in the number of peer lead Family Support Groups over the past number of years, going from less than 10 in 2000 to 83 today. She highlighted the valuable changes that have taken place as a result of the work of family support groups including a reduction in dependency on medical services and prescription drugs, and urged the government to reverse cuts that have been made to their funding.

Minister Alex White T.D. thanked the Family Support Network for the invitation and warmly welcomed those from around the country who had made the trip to the service. He also

thanked the religious representatives and his political colleagues for attending. The Minister highlighted the fact that his office had decided to mainstream and continue the funding for the National Family Support Network's Annual Work Conference in recognition of its importance to families and in responding to substance misuse across Ireland.

Minister White pointed out that there are many reasons to hold an event like this. It is first and foremost an occasion for family members to mourn their loved ones and celebrate their lives. For too long lives lost to drug abuse were ignored, not spoken about and even oppressed. Minister White said *'Events like this show us how far we have come as a society, not to sweep people's lives under the carpet and ignore their families'*. The Minister welcomed the contribution made by families to tackling the drug problem, the 'extraordinary and invaluable work' that the NFSN do for families and communities, and the drugs task forces for their role. He said that we must remember the stories of hope, of those who have turned their lives around, for inspiration.

Minister White highlighted that behind the headlines and the crime statistics are people, mostly young people who have been fatally affected by drug use, families that are no different to any other family in Ireland and who deserve to have their loss acknowledged. Minister White extended his condolences to, and expressed solidarity with, all those present who had lost loved ones.

Service of Commemoration and Hope

The next section of the mass was opened with a moving rendition of Sarah McLoughlin's *'Arms of an Angel'* by soprano Nicola Hendy.

Reflection

Father Edmond Grace then guided the attendees through a reflection, beginning by inviting them to appreciate the beauty of the church ceiling and the quilts that were a reflection of so many stories that bound those in attendance. He invited family members to be silent for a few minutes, thinking of the story and the person that brought them to the ceremony. He said that those people were present with the families that night and that they should take a few moments to spend time with their loved one before beginning the service. He finished by saying: *You're here to show your love for your family, to care for them so far as they need caring on their journey into the next world, and also to allow their love for you to shine. Their love is always with us.*

Testimony

Brendan Doyle (Wexford FSG)

"It's a great honour for myself and Hilda to be here tonight. We would like to share our story with you. We have been living with addiction in our home for many years. It was only after the death of our young son Mark, 9 years ago, that we became very isolated. We

found our local family support group and learned ways to take care of ourselves. On this day last year, we got a call to say another one of our sons had taken ill and was in hospital. Later that month sadly we lost another one of our sons. While we were devastated, we found a way to deal with it in a different way. We believe this is because of the amazing support we received from the staff and our friends in the family support network. What really helped us was that we started to attend the monthly bereavement group, just one month before our son died. The counsellors there helped us to try and get on with our own lives. The loss of a child leaves a hole in your life that can never be filled, but without the National Family Support Network, our local family support group and our friends we would never have found our way. We encourage others going through this to do the same”

Calling of the Groups

Paul Browne from Ballymun FSG and Kathleen Cronin from Ballyfermot Star FSG called representatives from all of the 83 FSG’s and 7 family support networks to the altar, each holding candles. There were so many family support groups present they could barely fit on the altar; a testament to the growing role of families in supporting one another and responding to the impact of substance use in their communities.

One Minutes Silence

When the families had filled the stage, a one minutes silence in remembrance of lost loved ones was led by **Kathleen Wynne, P2P**. This was followed by an uplifting and hope-filled rendition of Labi Siffre’s *Something Inside So Strong* by the children’s choir. This was followed by two readings from **Gordon Jeyes, National Director of Children and Family Services** who read two sombre and beautiful poems by English poet Mervyn Peake, including *The Vastest Things*:

The vastest things are those we may not learn.
We are not taught to die, nor to be born,
Nor how to burn
With love.
How pitiful is our enforced return
To those small things we are the masters of.

Message on behalf of the Pope Benedict XVI

Geraldine Moloney, Circle of Friends FSG read a greeting from the Pope to families in attendance. He cordially greeted all those attending the 14th Annual Service. His Holiness

prays that the lord may dispel the darkness and despair by all those affected by drug abuse. He entrusts all associated with the National Family Support Network to the protection of the Blessed Virgin Mary that she may guide them towards her son, Jesus, the source of all true hope. He stated his appreciation for the work carried out by the National Family Support Network and gladly imparted the apostolic blessing upon those families present tonight.

Poem on behalf of UISCE & SAOL

Ruaidhrí McAuliffe from UISCE represents people who use substances, ex substance users and people who use services. Ruaidhrí acknowledged the loss and memory of Tommy Larkin, and particularly Christopher Flood who's anniversary was on the day of the service, and who was very important in establishing UISCE. Ruaidhrí introduced **Michelle Kavanagh** who read a powerful poem documenting her experiences of being a drug user and its impact on her family:

7 visits

The first time I went home stoned
My mother ran me a bath
I just got sick on the toilet mat
She didn't know what was wrong with me
But I was 15 and on drugs you see.

The second time I went home
She asked why I was doing this to her and cried
So I cried too, "I'm doing great now, ma" I lied
But sure what's the point, they're all dead wide
Just see what I can get and then run a mile
So I ask for a lend and phoned my dealer with a cheeky grin
Hah, no matter what I do they'll always give in!
No knowing when I leave my mother's in tears
Cos now I've brought back all her fears
Every day and night she cries
Waiting for that call to say I've died.

The third time I went home my sister wouldn't let me in
But cried looking at me I'd gone so thin.
My brother called the Guards. I know for him that was hard
But I couldn't blame them, they'd had enough
Me coming and going, robbing their stuff.
So now that's it, they've given up.

The fourth time I went home, feeling all alone
Passing the houses all nice and cosy
Families all together having their dinner
I sit in the cold having a nosey
The streets are empty, no one out, not a sinner

They all start to leave with a hug and a kiss
I sit with tears, cos that's what I really miss
How's my family doing, I start to wonder
Do they think about me when it's lightning and thunder?
Sleeping in a doorway waiting for a fix
But then why should they when all I ever did was leave my mother in bits.
So many years worried where I was
And I didn't give a shit, I was me own boss.
14 long years living here, there, everywhere.
How did it take so long to see what I lost.

The fifth time I went home I was clean
But my fella rang
And the doubt in her eyes I didn't want to be seen
And I was doing well, two months clean
But here I go again, back on the streets without a bean
Thinking of my family who for me would always care
Even after all the hurt and pain I caused
And all I could do was live in shame
Any reason to stay on drugs 'play the blame game'.

The sixth time she visited me in hospital
My fella had left me black and blue
So she took me home – what else could she do?
I caused nothing but pain and misery
But was too stoned to see.
A whole family was falling apart
And all because I was breaking their hearts
What can they do? How can they help?
When right now all you care about is yourself.
You never stop for a second to think how they felt.

The seventh time I went home she hugged me tightly
Cos many times I'd sworn I was clean
But to me it was only a dream.
Now I know dreams do come true and when I've finished reading this, you will too!
Cos I'm doing great now – yes, I'm one of the few.
You see, starting SAOL changed my life in ways I never knew
I've learned how to forgive and be forgiven
And how the drug changed every part of the life I was living
Family, friends, housing and health
All these I'd forgotten about but now I know my health is my wealth

And living life to the fullest with my family all around me
This is the happiest in my life I've ever felt.

I would like to thank my family and SAOL for helping me to get where I am today and for never giving up on me – they stayed by me until I was free.

Following this, **soprano Nicola Hendy** performed a beautiful rendition of *Somewhere Over the Rainbow* from the musical *The Wizard of Oz*, with the most famous, uplifting line *If happy little bluebirds fly beyond the rainbow, why oh why can't I?*

Bishop's Address

The **Most Rev. Bishop Eamonn Walsh** addressed the attendees, opening by expressing sadness and regret at the lives lost, represented by the quilts hanging in the church. Praising the Family Support Network he said:

Were it not for groups like NFSN where would we be? We all know that feeling when chaos, denial, disbelief and shame come into our lives, where would we turn? There's no light in the darkness and then someone points us in the direction of the Family Support Network and the light begins to shine.

He went on to discuss how deep in the heart of everyone is the inner goodness to treat one another as family, as Jesus Christ reached out to those on the margins, those who were outcast and those who are kept in the dark. We are called here to be the light, each one of us.

The Lord's Prayer / Blessing of the Keepsakes

Various religious representatives said prayers of the faithful and prayed for many things including the keepsakes that were brought to the altar, blessing for everyone present, and prayers that those present may continue to be the light that shines in the darkness, and that they remain each other's brother and sister on the journey of life.

Prayer

Reginald Oko-Flex Inya, Coordinator, New Communities Partnership then lead a prayer, after thanking the National Family Support Network for the privilege of being there. He first highlighted that what makes us human is not the colour of our skin, but the fact that we all hurt, and we can all be one another's shoulder to cry on. He led a prayer that could be said by anyone of any faith. In this prayer, he prayed for the strength of the family, family values and for all families to be led back to God.

After Reginald's prayer, **St. Mary's Youth Club** performed a joyous interpretation of the song *The Climb*

Gratitude

Siobhan Maher of the National Family Support Network thanked a long list of people who had contributed to the success of the commemoration, those who were named included:

- Minister Alex White for address and support
- Councillor Pdraig McLoughlin
- Assistant Garda Commissioner John Twomey
- Gordon Jeyes and all other public representatives
- All the people who read and performed on the evening
- St. Mary's Youth Club
- Francesca Arkins Dance and Stage academy
- Father James, Sister Marina and staff of Our Lady of Lourdes Church for their cooperation, Mary Leech for donating the beautiful flowers
- Brian Tracey, Benny Lynch, Richie O'Niell and Darren Brady for the sound and lighting.
- Religious representatives for attendance
- Brian, Darren and Gay for hanging the quilts
- The Service working group
- All the Family Support Groups and family members
- Sadie, Clara and Megan from the NFSN

Siobhán highlighted that a benevolent fund, for family members in the initial stages after death of a loved one, was running low and contributions were needed. Collection baskets were at end of church for people to donate on the way out. All attendees were invited to a nearby hotel for light refreshments and music after the mass.

Final Blessing

All religious representatives and the congregation were led by Bishop Éamonn Walsh in the following prayer: May the God of peace with you. May the God of love enfold you. May the God of hope give you courage and joy and may your goodness return to you when you need it most. May the blessing of almighty God be with you and your family.

Exit Song

St. Mary's Youth Club finished the evening with a joyous rendition of the gospel song *Oh Happy Day*. The congregation clapped along as they left, and made their way round to a nearby hotel for an evening of refreshments and entertainment.



A photograph of the beautifully decorated Our Lady of Lourdes Church on Seán McDermott St, where the ceremony was held, taken on the day of the ceremony.

Part Two: Evaluation

Introduction from the literature

The Effects of a Drug Related Death on the Family

'Finding a new normal can take 5 years after the death of a child. Counselling and support groups were the most common supports utilised by those experiencing grief. Groups became less important for some after 4 years, although were still used by a significant proportion of families' (Feigelman, 2012).

This quote is from a comparative research project which reviewed the experiences of 571 parents who had experienced a child's death either related to suicide / drug death or a death from natural causes. The study found that while there were no differences in relation to grief and mental health problems between parents who were coping with a death by suicide or a drug related death, there were significant differences when parents in these two groups were compared to parents whose children had died from accidental or natural causes. The researchers concluded that the difference was due, in part to the 'powerful and intense stigma against drug use and mental illness, shared among the public-at-large, imposes challenges in healing of immense proportion for these parents as they find less compassionate responses from their significant others, following their losses' (Feigelman et al. 2011).

The role that stigma can play in the grieving process is noted:

'The cause of death carries a stigma for the deceased, such that it may not be legitimate to grieve for their loss. The cause of death also carries another stigma, such that the bereaved may feel guilty and unworthy of their rights to grieve' (Guy, 2004).

Grieving is a complicated process and bereaved parents of substance misusers contend not only with stigma but also issues such as suddenness of death, the age of the death of the child (which tends to be young), and the fact that the deviant nature of drug use may have led to parental disapproval. It is also possible that *'the death itself might reveal a relative or friend as drug user for the first time'* (Guy 2004).

There is also evidence to suggest that the quality of the relationship with a deceased child has an effect on the ability to grieve (Hayslip, 2004). Where a parent's relationship with their drug using child has become strained through drug use, this may have a negative effect upon grieving following the child's death.

Drug Deaths and Prevalence

The National Family Support Network has played a significant role in the development of the National Drug related Deaths Index.

‘When compiling background information for the first Service of Commemoration and Hope in November 2000, the Family Support Network could not locate accurate numbers of drug-related deaths and deaths among drug users. This was because the current system could only extract data on direct drug-related deaths. Following the service, Dr Joe Barry, medical advisor to the National Drugs Strategy Team, with the co-operation of parents, reviewed death certificates of their children who had died as a result of drug use. This review found that many of the drug-related-deaths and deaths among drug users were miscoded.’ (Lynn & Long, 2005).

Following this discovery and review, a group was established to explore the possibility of an index for drug related deaths. The National Drug Related Death Index (NDRDI) was founded in 2005 as a result of advocacy efforts by families of substance misusers in Dublin, through the National Family Support Network. They called for the state to measure the extent of premature death among drug misusers. This information would give a more accurate understanding of the extent of the problem and would enable the State to respond in a timely manner.

The National Family Support Network continues to play a role in this committee, with the list maintained by the Health Research Board and funded jointly through the Department of Health and Department of Justice

Figures from the NDRDI in 2010 show that there were 575 drug related deaths within Ireland that year (Health Research Board, 2012). This figure is considered to be a conservative estimate due to the way in which data is collected and that some deaths by poisoning (overdose) will not be recorded.

A documented history of drug dependence or drug use is not available in all cases, leading to an under recording of the total number of non-poisoning deaths in the drug-using population (HRB, 2012)

Irish data is reflective of wider international trends. In America

‘drug-related deaths have more than doubled since the early 1980’s. There are more deaths, illness, and disabilities from substance abuse than from any other preventable health condition. Today in the UK, one in four deaths is attributable to alcohol, tobacco, and illicit drug use’ (NIDA: 2013).

The Ceremony of Commemoration and Hope Contextualised

At the first Service of Commemoration and Hope in 2000, less than 10 family support groups, all located in the Dublin area, were represented (Lynn, 2012). It has since grown to represent 83 family support groups and 7 networks across Ireland. The increase in popularity of the event can be understood in context of the literature given the multiple challenges faced by families struggling to cope with the death of a family member through drug use.

Theorists writing on drug related deaths and how families struggle to come to terms with this experience highlight the role and requirement of developing meaning from such loss. The need to do this as a healthy part of the grieving process and the importance of positive supports in this regard is highlighted (Guy, 2004; Shapiro, 1994). The service of commemoration and hope plays an important role in this regard for the communities that it serves across Ireland and for the many families and individuals attending.

The Evaluation – Methodology, Discussion and Findings

Evaluation Methodology

Random semi-structured interviews were conducted with those who had attended the commemoration and also attended the after function held in a nearby hotel. Interviews were conducted until there was a saturation of response, i.e. following the last four interviews no new information was raised. Interviews were conducted between 9.00pm and 11.00pm by two interviewers at the social event after the ceremony. There were 17 interviews in total.

Individuals' comments were written and read back to the respondents for confirmation of meaning and tone. The questions asked centred around the following themes:

- What does the ceremony mean to people, what does it provide them?
- Can the supports / benefits provided by the ceremony be accessed from anywhere else?
- What was their favourite aspect of the ceremony and what would they change or improve for the future? Do they have any suggestions for a theme for next year's ceremony?
- What supports do families need in relation to addiction related bereavement?
- What are their views on the provision of overdose training and naloxone for family members with an active drug user in the family?

Discussion of Interview Responses

The Role of the Service in People's Lives

There was a very consistent view of the service and the role it plays in people's lives. The main themes that arose through the interviews were that the service provides a place where they can grieve and remember, without being judged, and the importance that this holds for them. They noted that the supports facilitated feeling of peace, love and connectedness, and that the service had a vital role in supporting appropriate memory and grieving for those lost.

This theme of grieving with stigma or judgement reflects the research findings, which highlight the challenges that families face in relation to stigma, societal judgement and the complications this brings for the grieving process. The comments below reflect these points:

It's very important to me. It's very touching. Absolutely lovely. When I'm here, I'm on the same level as others.

It's a celebration of life and a chance to say that our loved ones are not forgotten. It gives me comfort, knowing that I'm not alone and that others won't judge me in my grief.

It was lovely, supportive and relaxing. It shows that there are people thinking about those who have been through this, and willing to make an effort to make them feel supported and like their not alone.

Respondents also highlighted the role of friendship and connection to others and how this helped contextualise and support their grieving or experience.

It was something else, like nothing I've ever been to, I felt not alone anymore.

It's very uplifting, I get an awful lot from it, spiritually and I find inner peace. I feel very emotional and I get so much strength from it. It's lovely to be with friends, it's so different than a night out, it's very meaningful.

There is a fierce friendship thing about it. You are friends for life with the people you meet at these events.

Many respondents identified the role of the ceremony in providing hope, peace and meaning. These comments again reflected the themes identified through the literature: the need for communal symbols to provide meaning, to validate their grieving and to join people in solidarity, providing a context for their experience and hope for the future.

It's out on its own, it encourages me to look at things differently to realise that there is hope and recovery.

It was amazing, the fact that the children were there was a ray of hope. The poem was amazing it brought back memories and it was hopeful and she was living proof that you can work through it. The church was full and the majority of people there were affected by addiction.

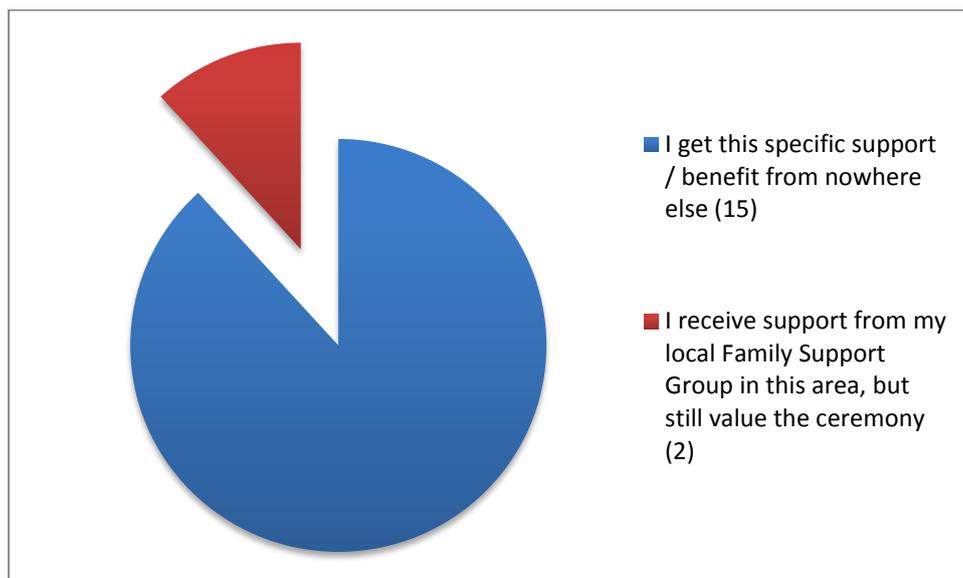
It gives me peace. It means everything to me. You think you're alone in this, and then you come here and you feel so much better.

For the majority of respondents the ceremony is a vital part of the year and is looked forward to. Respondents were clear that while their family support group attendance was essential to them, the ceremony played a role in their lives that was not met by other services or events.

It was very moving and emotional. It was lovely, it's the third time I have come and I will always go now, I so look forward to it.

Support groups provide enormous support but this commemoration is unique.

Table 1: Respondents and their Perception of the Commemoration



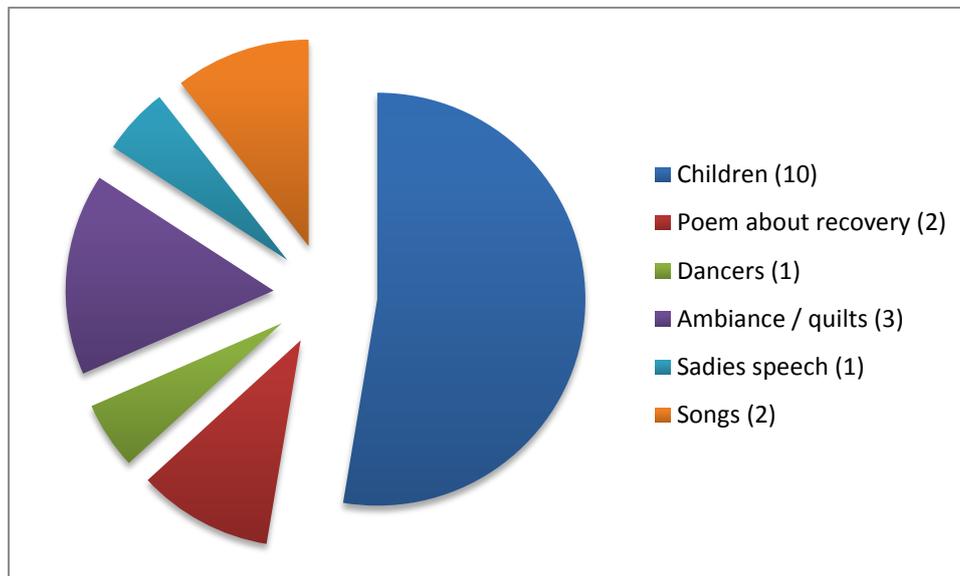
Another theme that arose through a number of the interviews was that the service played an important function in assisting communities to not forget the pain that they, as a whole had suffered.

There was a lovely sense of nation wide community spirit. It reminded people what an important issue it is across the country. It's my first time. I came with mum who comes every year. It gets forgotten except for ceremonies like this.

Respondents Favourite Aspect of the Ceremony

The atmosphere and tapestries, it was a church but so different, they had changed it and the children were lovely.

Table 2: Respondents Favourite aspect of the Ceremony

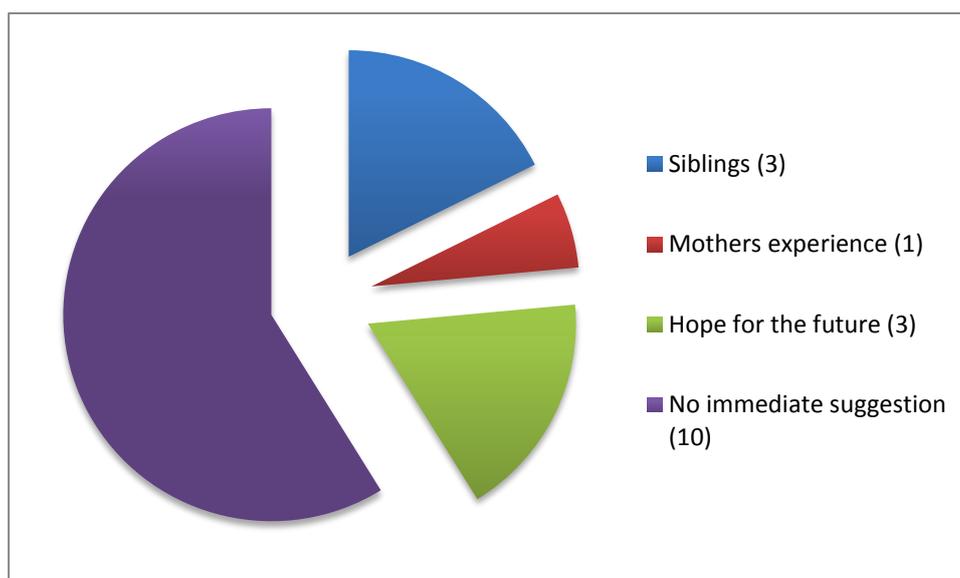


Respondents Recommendation for Future Ceremonies

The majority of respondents (14/17) could not identify any way in which the ceremony could be improved. The three comments that were made as part of the interviews, as to how the ceremony could be improved were:

- *I would have liked to have heard from a mother about how they recovered after the loss of a child.*
- *I would hope that there is no need to mention funding as the government has changed its policy.*
- *The politicians, they should have less speaking time, so there is more time for the ordinary people to talk.*

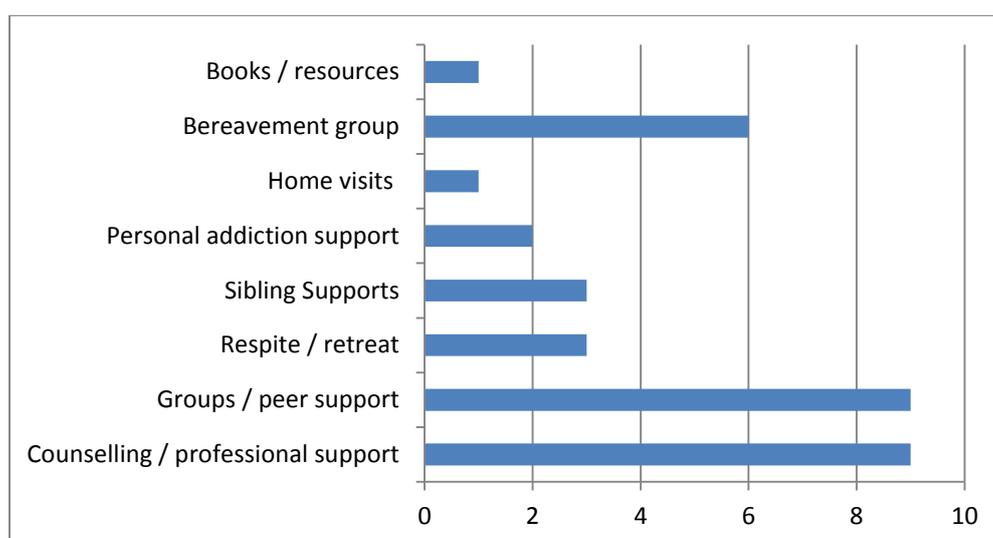
Table 3: Suggestions for Next Years Theme



Respondents' Identification of the Supports Needed by Families

As the table below indicates, there were several supports identified. Respondents could raise as many suggestions as they thought useful. Peer support (through Family Support Groups) and professional counselling were considered the most useful. This response reflects the actual engagement of supports by the cohort in Feigelman's study (2012), which saw counselling and peer supports as the most attended and the most useful supports for grieving parents over a 5-7 year period. Below the table are comments from the respondents in relation to this need for supports.

Table 4: Respondents views of the Support required by families managing a substance use related death



Speaking as one who knows, you need somewhere where you can speak freely about what is going on, without fear of upsetting your family - cause you can break down

and it's alright. People who don't know look down on you when there is a problem in the family with drugs.

Support, counselling and family support groups. The loneliness is the hardest, only those that have experienced it can understand.

Support for children and siblings there is nothing for them and they need a different type of support.

Sometimes they need addiction support. My brother took to the drink. They need not to feel alone. They need help accepting it.

Naloxone¹ and Overdose Training

All respondents were in agreement that families living with an active substance misuser or someone on methadone should have access to both overdose training and naloxone. Three respondents agreed that this should be available for those that wanted it, or only with adequate training and supervision.

It depends, not every family will want it, some will be terrified of the responsibility, but for those that want it, yes.

Yes, absolutely, but it should be monitored.

Summary

Research highlights that there are multiple challenges faced by families and parents who lose a child or family member to substance use related causes. These challenges include stigma, isolation and judgement, a complicated relationship with their own grieving, difficulty in contextualising the death and their own right to grieve.

The need for appropriate social and professional supports for these groups is evident. The commemoration ceremony can be seen as one important communal occasion which in some ways address the multiple challenges for parents who are dealing with the death of a loved one by drug related causes.

Respondents see the ceremony as having an important and unique role in their lives, many return each year and look forward to the occasion. The ceremony plays a specific role in allowing and validating people's grief in a supportive and non judgemental environment, facilitating friendships, social connectedness and the development of support networks.

¹ Naloxone is a drug that reverses opiate overdose (e.g. heroin, methadone, codeine) and can be kept by an at-risk person or someone close to them to use if needed. It is similar to the way people with diabetes can keep insulin with them in case of emergency.

Respondents were clear in the identification of effective supports for families managing the death of a loved one through substance use – peer group support and bereavement counselling. They were also unanimous in their support for overdose and naloxone training for family members. These comments are useful in validating and providing information for the National Family Support Network in advocating on behalf of affected families.

Different facets of the ceremony were appreciated by attendees, with people naming six particular aspects as their favourite. However by far the most memorable part of the 14th annual commemoration ceremony was the involvement of children, who brought a sense of hope, continuation and renewal. This is most fitting as the theme of the service was *Our children, Our family*. Those attending noted that the ceremony was an occasion to remember and celebrate their own families as well as rejoice in the connections that they had made with their peers through family support groups, conferences, services and other events throughout the year.

Recommendations

Increased Engagement of Drug Services in the Service

Invite local services to participate in the service, stating the role that they play and their importance to families. For those services that are not able to attend due to reductions in staff hours and general resource constraints another appropriate way to show their support of the event could be considered, such as cards with messages that could be brought to the altar, or some other appropriate symbol or gesture. There are over 150 substance related services across Ireland and messages from these services could be a strong symbol of the national support for families within support services.

It should also be noted that attendees provided a direct recommendation to the National Family Support Network staff: that those who fund services responding to substance misuse should attend the ceremony and show an appropriate degree of respect for families affected by drug use.

The Theme of Siblings and the Need for Supports

The theme of sibling support and appreciation could be considered as a theme for next year's commemoration service, given that themes of hope and the supports of mothers have been a focus of past ceremonies, and the need for sibling support came up through the evaluation discussions.

Continued Role of NFSN as Advocates in Promoting Services for Families Dealing with Bereavement from Addiction

There was a clear call from all respondents for more supports for families dealing with drug related death. Respondents identified the top three supports required as being counselling,

peer supports and bereavement groups, the need for sibling based support was named as a particular gap within support services.

Overdose and Naloxone Training for Parents of Active Substance / Methadone Users

Families were overwhelming supportive of the NFSNs continued promotion and advocacy for Naloxone and Overdose training, within a structured and monitored programme for any family members of active substance misusers / methadone users who wished to avail of it.

Keep Up the Good Work

Respondents noted how professional, well organised and welcoming the event was. There was a great sense of appreciation for the work of the National Family Support Network and a clear message to keep it up!

References

- Feigelman, W., 2012. Devastating losses: how parents cope with the death of a child to suicide or drugs. New York: Springer Pub
- Feigelman, W., Jordan, JR., Gorman, Bernard S. 2011. Parental grief after a child's drug death compared to other death causes: investigating a greatly neglected bereavement population. *Omega*, 2011, Vol.63(4), pp.291-316
- Hayslip B., Henderson J. & King J. 2004. The relationship between adjustment and bereavement-related distress: a longitudinal study (2004). *Journal of Mental Health Counseling*. 26.2 (Apr. 2004): p98.
- Health Research Board, 2012. Drug Related Deaths and Deaths Among Drug Users in Ireland: 2010 Figures from the National Drug Related Death Index
Available at: <http://www.drugsandalcohol.ie/18905/> Accessed on: 04/03/2013
- Guy, P. 2004. Bereavement Through Drug Use: Messages From Research. *Practice*, 2004, Vol.16 (1), p.43-54
- Guy P. & Holloway M. 2007. Drug-related deaths and the 'special deaths' of late modernity. *Sociology*, Feb, 2007, Vol.41(1), p.83(14)
- Lynn, E. 2012: The Thirteenth Annual Service of Commemoration and Hope. *Drugnet Issue 41* (2012) Health Research Board, Dublin Ireland
- Lynn, E. & Long J. 2005. *Launch of the National Drug Related Death Index*. *Drugnet Ireland*, Issue 16, Winter 2005. Available at:
http://www.hrb.ie/uploads/tx_hrbpublications/DrugnetIreland16.pdf
- National Institute on Drug Abuse. NIDA website (<http://www.drugabuse.gov/patients-families>) accessed Feb 1/2013

Harvard Health website (<http://www.health.harvard.edu/fhg/updates/update1203b.shtml>),
accessed Feb 1/2013

Shapiro E.R. 1994. Grief as a family process: a development approach to clinical practice
New York: Guilford

Appendix

The cover of the booklet handed out to attendees on the evening:

