

The Mind Reader

MENTAL HEALTH NEWS, ARTICLES
AND INFORMATION

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CEO Message



Dear Mind Readers,

Welcome to the April edition of our MindReader publication. I am Acting CEO while our CEO Elizabeth Priestley is currently on a well-earned break.

In the last few weeks, we have continued supporting our community in various ways. I would like to mention just two of the ways we help influence and shape public policy through our advocacy efforts.

In mid-March, we participated in the NSW Electoral Commission's Equal Access to Democracy Disability Reference Group meeting. The group works to ensure that everyone who is eligible to vote in NSW council and state elections is able to do so in a variety of ways that suit them. It is vitally important that people with a lived experience of mental illness are able to fully participate in the democratic process and we are thankful to the NSW Electoral Commission for inviting us to join the working group.

We know that many people with a lived experience are able to vote by attending a polling station on or before Election Day, but we also know for others this is not possible. Fortunately there are other ways people can cast their vote which does not rely on them lodging it in person. We have committed to working with the NSW Electoral Commission to help promote the variety of ways in which people can participate in the upcoming NSW State Election in March 2019.

We have also been invited to attend a national leadership roundtable event looking into the complex social and emerging public health issue of loneliness hosted by Swinburne University in Melbourne later this month. The roundtable event will identify shared challenges that we face in combatting loneliness and help shape a high-level strategy for addressing loneliness through policy, research and community outreach.

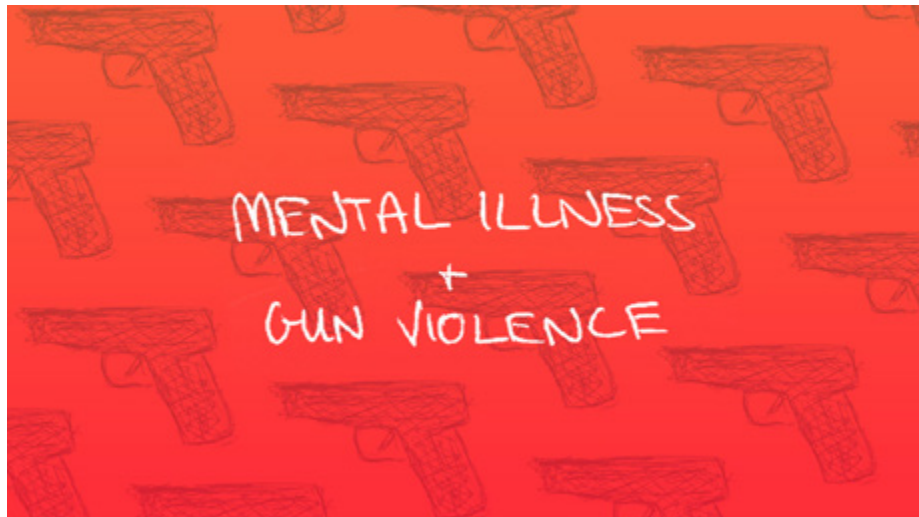
We have a role in contributing to this national dialogue as we already know that loneliness has a deep impact on a person's mental health and wellness. We also know that it is a benefit to our mental health and wellbeing when we are all active participants in our community.

I hope you enjoy this edition of [The Mind Reader](#) as much as I did.

Happy reading,

Marge Jackson Acting CEO WayAhead

Mental illness, violence and shootings



In the months since [February's school shooting in Florida](#), communities, lawmakers and young people themselves have been questioning what could have been done to prevent the loss of life and ensure that gun violence does not continue to occur.

In the immediate aftermath, [as President Trump cited the shooter's mental health as the cause](#), the conversation focussed on mental illness as the reason for many school and public massacres. The larger debate around causes has focussed on access to firearms versus the mental health of the shooters. Setting aside this dispute about the reasons for mass shootings, the repeated assertion that mental illness is the underlying cause has a number of impacts.

Mental illness and violence have a complex relationship, with a number of misconceptions and assumptions. The touting of mental illness as a major cause for acts of extreme violence is both [incorrect and harmful](#). In the aftermath of the shooting in Florida, various mental health professionals called for public figures to think about how they speak about violence and mental illness.

"[W]ithin hours of the shooting – before the name of the shooter was even released – non-medical professionals, including the Superintendent of Schools in Broward County, made their own diagnosis. They said that the shooter must be "insane"; [wrote](#) Paul Gionfriddo, the President and CEO of Mental Health America.

"There are millions of people in America living with serious mental illnesses who never have a violent thought in their lives. So why do we automatically assume that all shooters have mental illness?"

The American Psychological Association, the largest scientific and professional organisation of psychologists in the US, [echoed these calls](#).

"While law enforcement is still piecing together the shooter's motives, some public figures and news reports are focusing on his mental health. It is important to remember that only a very small percentage of violent acts are committed by people who are diagnosed with, or in treatment for, mental illness," said Jessica Henderson Daniel, the President of the American Psychological Association.

As the Australian Government's Mindframe National Media Initiative sets out, [people with mental illnesses are no more likely to commit violent acts](#) than members of the wider community. Mindframe sets out guidelines for organisations and people like journalists, health care workers and the police, on how to responsibly report on mental health and suicide in the media. Responsible reporting of mental illness in the media is important because of the stigma and myths about mental illness that continue to persist.

People with mental illness are no more likely to be violent than those without. In fact, [only 3 to 4 per cent of all violence](#) in the US is attributable to people who have been diagnosed with mental illnesses such as schizophrenia, depression or bipolar. A study in the US found [particular demographic groups had an increased risk of violence](#), namely younger individuals, males, those of lower socioeconomic status, and those with alcohol or illicit drug use issues, regardless of whether mental illness is present or not. Although there is a slightly higher

likelihood of violence among those with complex mental illnesses, [much of this could be attributable to factors](#) such as substance abuse issues, having a history of violence independent of the mental illness, or not receiving appropriate treatment.

People with mental illnesses are also much more likely to be [victims of violence than others](#). They are at a higher risk of homicide, suicide and self-harm. In cases where people with serious mental health conditions are involuntarily admitted, such as schizophrenia, severe depression or bipolar illness, the majority of situations arise [not because people are a danger to others](#) but rather, because they are a danger to themselves.

This increased likelihood of people with mental illnesses being victims of violence manifests in tragic ways. In the US, those with mental illnesses are much [more likely to be assaulted by others or shot by the police](#) than be perpetrators of violent crime. Closer to home, the ABC recently reported that of 35 police shooting deaths in NSW over the last 20 years, [more than half were of people who had mental health diagnoses](#).

NSW Greens MP, David Shoebriidge, has been looking into deaths in NSW due to police firearms. In the [ABC report](#), Mr Shoebriidge identified the combination of two factors, the under-resourcing of mental health facilities and a lack of training for police in dealing with mental illness, as what lead to these deaths. Last year, the Queensland coroner recommended that the police [treat mental health as "core business"](#) in the wake of five deaths of people, all of whom had a history of mental illness, who were shot and killed by police.

As policymakers and politicians argue about the causes for gun violence, as organisations [tally how many shootings happen in US schools](#), and closer to home, as those with mental illnesses make up more than half of police deaths in NSW, it is vitally important to find ways to talk about mental illness and violence with nuance, understanding and an informed awareness.

As Jessica Henderson Daniel, of the American Psychological Association, [said](#):

"Framing the conversation about gun violence in the context of mental illness does a disservice to the victims of violence and unfairly stigmatizes the many others with mental illness. More important, it does not direct us to appropriate solutions to this public health crisis."

Now, as ever, finding appropriate solutions is hugely important and should be the focus of researchers, policy makers, politicians and members of the community.

By Tasnim Hossain

Tackling mental health through NRL

Among many other sporting codes, the National Rugby League has been working on supporting better mental health of their players, supporters and community. Earlier this year, as part of their Festival of Indigenous Rugby League, the NRL ran a suite of programs alongside to encourage wellbeing and good mental health.

<https://www.instagram.com/p/BfFRaxsBSBN/>

The programs included a wellbeing and employment expo, wellbeing workshops for all the teams playing in the festival and a three-day Indigenous Youth Leadership Summit, focussing on mental health and resilience.

A number of high profile players were at the festival, including Indigenous All Stars players, Greg Inglis, Johnathan Thurston, Dane Gagai, Wade Graham, Jack Wightton and Joel Thompson.

The festival was supported by the Federal Government and the Minister for Indigenous Health, Ken Wyatt AM, attended.

<https://www.instagram.com/p/BfH-Fhphgu4/>

“Sport, in particular rugby league, plays an important role in many of our communities, connecting people and empowering them to make positive changes in their lives,” Minister Wyatt said.

“Team sports offer social connections, build personal relationships and a sense of belonging.

“Through the partnership at this festival, the good news on mental health is getting spread out to thousands of people here and through their friends, families and social networks across the many communities from which they have come.”

<https://youtu.be/EUPbOavYH70>

“This festival complements the NRL’s State of Mind programs, which focus on early intervention and reducing the stigma often associated with mental illness.”

The NRL has developed a number of initiatives as part of their State of Mind program. The program has the support of organisations such as Headspace, the Black Dog Institute and Lifeline.

For the last few years, the NRL has invested in the program, which aims to reduce stigma in the wider community through their profile, encourage help-seeking and support players to become mental health advocates. They have a number of high profile ambassadors, including Joel Thompson, Dane Gagai and Tariq Sims.

<https://youtu.be/Dw3GrMK7fjo>

With so many people connected to NRL, through playing it or supporting it, these initiatives use those connections to support better mental health in specific groups like Indigenous people, young people and in the wider community.

By Tasnim Hossain

Writing responsibly about mental health



One of the most significant ways of sharing experiences of mental health is through storytelling. Storytelling can be powerful and impactful, but writers of mental health have to be mindful about the language that is used. Writing about mental health also comes with a responsibility to report without perpetuating negative stereotypes or stigma. Many terms are used to describe people's mental health, with some carrying different, and sometimes harmful, connotations.

WayAhead has internal guidelines for sharing personal stories from people with lived experiences. They were developed to ensure that these stories contribute to destigmatising mental illness, share a message of hope and recovery for others, and empower people to share their own experiences with mental health.

However, it is not uncommon to see media outlets using mental illness as a label for someone who has committed an offence, which can perpetuate a general distrust of people with mental illness. Words such as 'sufferer' and 'victim' convey a picture of someone who is not in control of their mental health. Some people prefer the terms 'survivor' or simply 'someone living with mental illness', which can help to separate an individual from their mental health.

WayAhead spoke to both Everymind and SANE Australia Media Centre, co-authors of the [Mindframe for Media Professionals](#) guide about how the media should report on a person with a mental illness.

According to the Mindframe guide, choosing accurate and respectful language is very important when reporting on someone living with mental illness as it is easy to stigmatise mental illness by using colloquial language or terminology that is confusing or used out of context.

Ellen Sproule, Senior Media and PR Advisor for SANE Australia, the national mental health charity, spoke about the fact that there is no industry standard or guidelines about the right terms to use.

"From SANE's end, we may occasionally use 'consumer' and 'service user' in the office. However, in all external communication to the public we say, 'people living with mental illness' [instead of] the terms 'consumer' and 'service user'... people outside the mental health sector don't understand these terms in this context," explained Ms Sproule.

A consumer or service user are neutral terms that can be used describe people living with mental illness who are using certain health services, but may also alienate those who do have a lived experience of mental illness but are not currently using any services.

"In terms of terminology to use in the media for people with lived experiences of mental health issues, we recommend saying something along the lines of:

[NAME] lives with schizophrenia instead of [NAME] is a schizophrenic, which we wouldn't recommend, as it labels a person by their illness," recommends Ms Sproule.

In addition to using appropriate terminology, it is also important to recognise that disclosure of a persons

mental health may not be relevant to a story at all, even if the subject does happen to be living with mental illness. Irresponsible reporting of people's mental health in the context of particular stories can reinforce negative and harmful stereotypes.

Marc Bryant, the Program Manager of Mindframe, has publicly spoken about the connection between violence and mental illness and how this perpetuates myths about mental illness.

"The main myths are that people who are mentally ill are violent, dangerous, untrustworthy, unpredictable when the facts that tell us many violent people have no history of mental illness and that most people who are mentally ill have no history of violence. People with a mental illness are much more likely to be victims of violence and crime than as perpetrators," said Mr Bryant [in an interview with ABC Radio National](#).

As the Mindframe guide recommends, it is important to consider whether mental illness is relevant to a story. The speculation around many stories which disclose or theorise about someone's state of mind can contribute to stigma, discrimination and misinformation about mental illness. As with any story, it is vital to check that representation of people with lived experience of mental ill health is responsible, fair and accurate.

By Cindee Duong

Research into how parents support young people living with mental ill health



It can be hard for parents to know what to do when their children are experiencing mental illness, particularly as they get into adolescence and young adulthood. Research indicates that how a parent responds to their child's mental health diagnosis can have an impact on the young person. Mental health policy, in Australia and overseas, is also increasingly recognising the role that parents and carers can play in the wellbeing of a young person, as well as the need to give them support. However, there is little research into what parents actually do to support their children who have mental health diagnoses, and what effect these actions have. For the last few years, Dr Anne Honey, senior lecturer at the University of Sydney, has been researching just that.

For her post-doctoral research, Dr Honey conducted in-depth interviews with both parents of young people, aged 15 to 24, with mental health diagnoses, as well as young people themselves, to better understand some of the actions that parents undertook for their children.

“It was actually amazing how many different types of things parents did. I don't think a lot of people realise how complex it is and how many different things parents are actually doing to try and support young people, with varying levels of success, but they try lots of things. And young people reported these things as well, not just parents,” said Dr Honey in an interview.

Her research found that even though parents reported a wide range of different strategies, there were particular categories of actions that parents undertook. There were four areas in which parents supported their children and tried to influence their child's experiences: appropriate treatment; positive activities and actions; positive thoughts and emotions; and an ordinary life.

Strategies supporting appropriate treatment might have included making appointments with health professionals, paying for treatment, transporting the young person or providing a history to health professionals. Things that promoted positive activities would be things such as praising positive behaviour, like exercise, or using their authority to make the child go to school, or not drink alcohol. Parents might have promoted positive thoughts or feelings in their child through providing happy experiences to look forward to, like holidays and treats, changing the home environment to be less stressful through avoiding conflict or managing siblings, or even sharing their own experiences of mental health issues. Parents also took action to support their child in having as ordinary a life as possible, through things like treating the young person normally, as they would their other children, explaining the situation to teachers or other family members when needed, and keeping the diagnosis from others to protect their child in other situations.

“Because [parents] used a lot of strategies, if they saw improvement in the young person, it was very hard for them to say which of the strategies they were using, if any, were working, because, of course, they were also seeing health professionals and doing other things as well,” said Dr Honey.

“A lot of the strategies they used were also quite long term, things like trying to make the person feel loved

and telling them that they were valued in the family. They did it to raise the young person's confidence and self-esteem but of course, that's such a long-term thing. Who knows if it's going to work in the short-term?"

Some of these methods that the parents in the study reported using may already be familiar to others with children who have mental health diagnoses. However, since there has been limited research focussed specifically on cataloguing and analysing these actions, a more informed understanding is important in order to learn from what parents do to help and what works.

"We looked at what's influencing what parents are actually doing and there were essentially two things: what they knew, or what they believed about mental illness or about the young person's situation; and then their ability to actually put the strategies that they thought were the best into action," said Dr Honey.

"Some of the parents had experienced their own mental health problems or had in their family... others had absolutely no idea so it was a very steep learning curve for them. I do think that the ones who knew the most at the start were the ones who had people in the family who'd also experienced mental health problems. What people are getting from the media, it's not enough. I guess it's never going to be enough, is it? You're not going to pay attention to that unless it's affecting you."

What parents actually do, where they get their strategies from and what really works are all things that Dr Honey is continuing to examine in her work. She is working on collecting more data to continue studying the strategies that parents put in place to support young people.

"The parents have got to get information from all different sources and then put it together to work out what to do in their very specific situation. What we're hoping is that this [new research] will be another great source for parents to consider when making their decisions."

Currently, Dr Honey and her team are taking submissions for a survey to further understand what strategies parents have used, and what they feel has helped.

"[We] took those strategies that we'd identified and put them into a survey to try and found out, on a larger scale, which ones are used most and which ones people find helpful," she said.

Dr Honey is hoping that her new research will help clarify some of those questions and concerns, providing some further insights that might help parents support young people.

"The main part of it, really, is about which strategies do parents actually find helpful under different circumstances so are there some strategies which are more likely to be helpful for a young person," she said.

"And then also being able to split that up into strategies more likely to be helpful with people who fit into that younger age bracket instead of the older age bracket, or does it differ between cultural groups or diagnoses, all the different things that influence how a young person might respond to what the parents are doing."

Ultimately, increasing those insights into what strategies parents use and how they work can help parents be more empowered when supporting a child with a mental health diagnosis. With the current lack of dedicated research into those actions, Dr Honey's research can help put into concrete action what we already know: that parental support can have positive benefits for young people experiencing mental illness.

"There's a lot to explore in that data but what we're hoping to be able to do is to use parents' own experiences to be able to let other parents know that these are the sort of strategies that others in a similar situation to you have found helpful," Dr Honey said.

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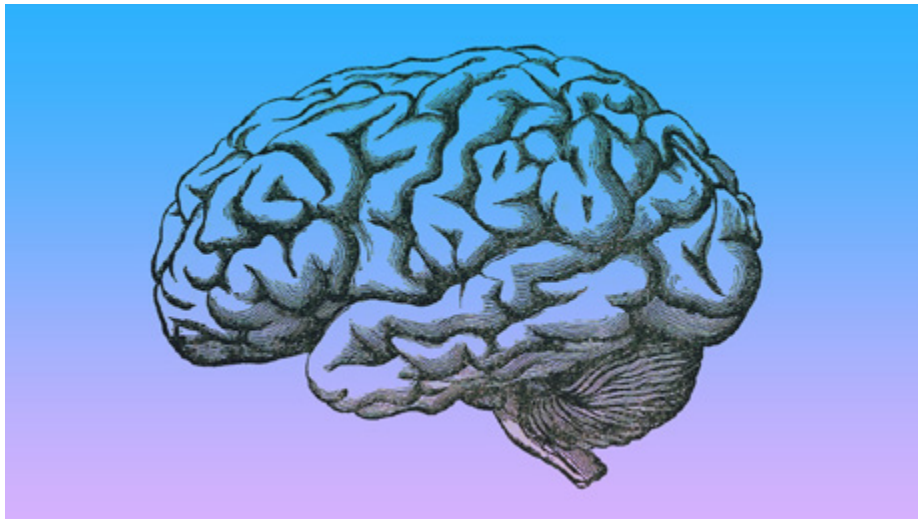
To participate in the current survey, visit: <https://redcap.sydney.edu.au/surveys/?s=PDNWW8TPP8>

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Understanding the neurobiology of anorexia



Improving the understanding how eating disorders work is a growing field of research. Recently, Wayahead received an e-bulletin from the National Eating Disorders Collaboration (NEDC) and we were very interested in the work that it explored. The NEDC, the research arm of The Butterfly Foundation, works with people and organisations to develop an evidence-based approach to preventing and managing eating disorders.

In the NEDC e-Bulletin, Dr. Andrea Phillipou gives an overview of current research into the role that neurobiology might play in eating disorders with a current, specific focus on anorexia nervosa. We corresponded with Dr. Phillipou about her work and have included her insights below.

“The piece I contributed to for NEDC was a bit of an overview of some of the research that has been done in relation to the neurobiology of anorexia nervosa around the world. I also went into a little detail in relation to some of the things we’re currently working on.

“In relation to the neurobiology research that I’m currently undertaking, my hoped for goal is to determine the underlying brain mechanisms that contribute to the cause and maintenance of anorexia nervosa to inform the development/improvement of treatment. Unlike most other mental illnesses, anorexia nervosa does not have a ‘biological’ treatment. For example, people with schizophrenia are often prescribed antipsychotics to alleviate symptoms; there are multiple medications used for anxiety and mood disorders; brain stimulation techniques have proven useful for a number of conditions such as depression – however, there is no medication or brain stimulation technique for anorexia nervosa.

“The treatments that we have for the illness are mainly psychological interventions (i.e. CBT or family therapy). These treatments show some efficacy but many patients remain under- or un-responsive to treatment. Anorexia is an often long and enduring condition, it has the highest death rate of any mental illness with one in ten of those diagnosed dying from the physical effects of starvation or from suicide, and a recovery rate of less than 50% among surviving patients. The efficacy of treatments for AN is severely lacking. One of the reasons for this is that unlike most other mental health conditions, there has not been a great focus on neurobiological contributions to anorexia, but rather a much greater focus on psychological and sociocultural influences.

In terms of timeline and history of the research I’m undertaking – I’ve been working on neurobiological research in anorexia since 2012 and it’s an ongoing endeavour. It’s my main research focus and I will continue in this area until we’re able to treat the illness effectively.

“The current findings in anorexia nervosa are mixed. There is not enough research to say with any certainty which brain regions, which neural circuits or which neurotransmitters are involved in the illness. We are the only group that I am aware of who work specifically on neurobiological research in Australia, and there are only a handful of groups around the world that work in this area. It is a growing area, but we need a lot more research in this field (and a lot more funding to be able to undertake this important research!). The findings of

our research have, however, indicated that there may be deficits in the communication between brain regions involved in how you think and how you feel you look in individuals with anorexia nervosa.

“Findings from our research have also suggested that a brain region called the superior colliculus and the neurotransmitter GABA may be involved in anorexia. This was implicated through some ‘biological marker’ research we have undertaken using eye movements in anorexia nervosa. Eye movements utilise very specific neural circuitry, so when we see specific deficits in eye movement control, it tells us about specific brain regions or neurotransmitters that are not functioning correctly (in this case, the superior colliculus and GABA).

“In this research we found that people with anorexia made tiny twitching eye movements when trying to fixate on a central stimulus. This type of eye movement is unique to anorexia, and not present in individuals with other mental illnesses. Therefore, we have proposed it as a ‘biomarker’ to identify people who have anorexia, and it may prove useful in identifying people with a predisposition to the illness in the future (with more research of course). However, as I mentioned, this is still preliminary research and there are no definitive brain areas or neurotransmitters that we can implicate in the illness.

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Research into eating disorders is still in its early stages. Researchers are still discovering new things about the brain and how it functions for those who have eating disorders. The NEDC is one of the centres around the world that is conducting and collating this vital research.

Read more about the [Dr. Phillipou's research in the NEDC e-bulletin here](#).

By Helen Murcutt

MIEACT – Better learning comes from sharing real life stories



MIEACT teaches mental health and well-being in ACT schools with a focus on volunteers with lived experience of mental illness telling their stories of hope and recovery.

“Mum, can you come to school and tell the kids and the teachers what it’s like to live in a family where someone has a mental illness? Now the kids have learnt my sister has schizophrenia, they won’t play with me. Their mums say it might be catching...”

Such were the words that triggered a school education program about living with mental illness, trialled in late 1987 under the auspices of the Association of Relatives and

Friends of the Mentally Ill (ARAFMI) and operating in Canberra as Mental Illness Education ACT ([MIEACT](#)) since 1993.

MIEACT is now a successful medium-sized Not For Profit organisation that has been promoting mental health and well-being in Canberra high schools and colleges through the lived experience of its volunteers for 25 years.

From its very inception MIEACT’s foundation program, the School Education Program (SEP), has attracted support at the highest level, with then ACT Chief Minister Kate Carnell sharing her story of anorexia to students in 1998.

MIEACT has grown its educational programs to include additional specific classroom training in stress management, positive body image for boys and girls, and is preparing to launch its latest program on bullying prevention later this year.

MIEACT also delivers mental health training for adults through workplaces and community groups.

“We share lived experience through all our programs,” Executive Officer Heidi Prowse said.

“There is research that shows having direct positive contact with someone living with a mental illness, or someone caring for a person who is mentally unwell, really does make an impact in the classroom,” she said. “For young people, listening to people’s stories is something they remember well beyond their graduation day. We make sure that our stories are really relevant and connecting with every person in the room.”



Heidi Prowse - MIEACT CEO

The Australian Research Alliance for Children and Youth (ARACY) report card 2018, published earlier this month, found rising levels of high or very high psychological distress among those aged 18-24 years and suicide rates among those aged 15-25. Of particular concern, 15.3 per cent of those aged 15-19 years were very or extremely concerned about bullying.



How does your team prepare before a big game? Do you use stress to perform or does it become too overwhelming? Why not book a MIEACT Stress Better Program like South Canberra 15s Netball Squad, and develop your team's skills on and off the field.

MIEACT's Bullying Prevention Program aims to address some of these concerns by offering support and education to people practising bullying behaviour; victims and bystanders early.

"Bullying is something that we are now recognising as a community that is very significant. We plan to launch in Term 2 this year because we know it is essential to be able to support our young people in understanding bullying behaviour:

"This means not just recognising instances of bullying and learning the tools to be able to manage bullying behaviour directed at you and others, but also teaching students and young people not to permanently label peers as "bullies", and to see it as a temporary pattern of bullying behaviour; something that can be worked on and changed."

MIEACT's Stress Better program encourages students in Years 11-12 to learn the difference between worry, stress and anxiety and teaches children how to manage all three before they develop into significant mental illnesses.

MIEACT is currently taking bookings for SEP, delivered into Canberra schools for free and into surrounding NSW schools for a nominal fee. You can also book a Stress Better workshop or register your interest in the Bullying Prevention Program by calling (02) 6257 1195.

To learn more about MIEACT's programs visit www.mieact.org.au

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National Mental Health Commissions calls for more investment into mental health for 0-12-year olds



The National Mental Health Commissioner, Dr Peggy Brown, has called on all levels of government to invest further in the mental health needs for children from birth to 12 years.

Speaking to The Mind Reader, Dr Brown said that the commission's latest call for action is aimed to help children identify and remedy mental health concerns early, rather than let them manifest into larger issues later in life.

"We think there is a strong argument for working with children at a very young age to identify any issues with their mental health and make appropriate interventions which can help prevent mental illness and any impacts later in life.

"We know that based on OECD research, Australia is behind the other OECD nations in the areas of mental distress and suicide for young people. So much of the way we help people with their mental health and wellness in Australia is based around prevention, so why should the mental health needs of young children be any different?" said Dr Brown.

Dr Brown also said that the extra funding is needed not only for the child in need but also for parents.

"Some of the investment is targeted towards parents too. We need to take a longer-term view here and not a short-term view. Investment early on can improve outcomes in adult life. Addressing a child's mental health concerns when they are children and not letting it go into their later life has significant impacts in their interactions with the youth justice system, their mental health, their employment and their physical health conditions. Investing early can be a wise choice and you reap the benefits now and in fact, decades down the track too," said Dr Brown.

Dr Brown recommended that any new funding needs to be part of an integrated approach across the gamut of service providers who would work with parents and children who may be at risk.

"This is not just about the infant or young child, this is about the family and the environment in which they live. It's about access points. Parents go to a variety of health practitioners and services; it's about identification and action, the concept of the 'no wrong door' really applies here. There should be a way in which we can work together when people are identified so that there is a way to support them to get them to the services they need. We need to break down the silos and learn how to work better together.

"We know that there are some really great practitioners and service providers out there already doing this stuff, but that is not always the case everywhere, we need to make sure that health practitioners and service providers are all well-equipped, comfortable and capable of helping a child with mental health concerns and their family," said Dr Brown.

Dr Brown believes that should there be an increase in funding for 0-12-year olds, then it should be spent on local community driven and informed strategies, that works across all key stakeholder groups and communities who would be involved.

“Structure the approach on a regional basis through the Primary Health Networks. They can tap into their regional hubs. Through the Primary Health Networks, they can create a Regional Mental Health Needs Assessment and Plan. As part of this it is important to get everyone in the community together to get their needs heard. It’s also important that any federally run investment links in with the state services who work with parents and children. What we are talking about here is a whole of community response and connecting everyone up, that’s how we will create real and effective change,” said Dr Brown.

Friendship in a time of loss



In the first of a series of articles on the organisations listed on the WayAhead Directory, WayAhead turns the spotlight on The Compassionate Friends NSW. The Compassionate Friends, or TCF, is recognised worldwide for the support and hope it offers families who are struggling with the deep grief of losing a child.

The organisation had its genesis in northern England in 1969 when a devastating flu epidemic caused the deaths of a large number of small children. Canon Dr. Simon Stephens, an Anglican priest, was working as a pastor at a large public hospital where many of the children died. He felt that the families might draw comfort from each other if he arranged for them to meet. It was this group of grieving families that became the organisation now known as The Compassionate Friends. It quickly became international and the NSW branch of TCF was established nearly 40 years ago.

The NSW branch provides support across the greater Sydney area as well as in regional areas across NSW. Its head office on York Street, Sydney, acts as a drop-in centre with one-on-one support from trained volunteers.

Monthly group meetings are held in the city office, in various metropolitan areas of Sydney and country areas of NSW, organised by volunteers trained by TCF. There is telephone support is also available. Every year, TCF NSW holds remembrance events as well as an annual weekend retreat that draws members from all parts of the state.

During a visit to Australia in 2015, Dr. Stephens said that there is a "conspiracy of silence" when children die in our society and we no longer have the time or the understanding of death that enables us to deal with parental or sibling grief, in particular:

Dr. Stephens told ABC Radio that this failure extends beyond individuals to government and religious institutions.

"Doctors, clergy and the caring professions still don't know how to adjust to the news that a child has died!"

In recent years the NSW branch has been working closely with its Victorian counterpart to raise national public awareness of The Compassionate Friends. Joy Rappo, the NSW State representative on the board of The Compassionate Friends Australia, has been working closely with the Victorian branch. She spoke to WayAhead about her experiences as a bereaved parent.

"I joined TCF in 2000, 11 weeks after my son Antony died suddenly following a medical procedure. He was just 18 years old. For well over a year, I would attend my local chapter meeting and not say a word. It was enough just to listen to other people's stories and get comfort from the sense of belonging because of the shared deep grief."

Joy became more involved in the running of TCF, first as a chapter leader herself, and then undertaking much of the administration of the head office in Sydney. She is committed to the wider community awareness of the work of The Compassionate Friends in this state.

The expansion of the work and profile requires concerted fund raising and TCF raised much-needed funds through the formation of its own TCF team in the last City2Surf. It will do so again in 2018 City2Surf. There are other fund raising projects in the pipeline.

Leanne Shanahan is the driving force behind this event and other future fund raising efforts. Leanne recently shared with WayAhead the background to her involvement with TCF.

“When I first lost my 21 year old son, Luke, in a car accident in 2015, I just needed to get up every day and do what I always liked doing and that was walking until one day the reality of losing Luke hit hard and I just crashed; I no longer had the energy to do anything.

“As my sad grief journey took a toll on me after 3 months, my sister knew I needed help. I went to my first meeting and felt part of this very sad club immediately; they felt my pain – the pain of the devastation of losing a child, something that nobody could ever imagine.

“I just wanted to give something back to this support group that helped me learn that there is a little light at the end of a very long sad tunnel. As I was always a walker, I decided to organise a group to walk in the City2Surf in 2017. We were able to raise \$10,000 and we are planning this year to have a team of walkers and runners again. We are hoping to double what we raised last year.

“I have just done a support leader group course and I am looking forward to opening up a new support group based in Narrabeen on the Northern Beaches to give back to those families that have sadly been dealt the worst card ever when you lose a child.”

In 1969, The Compassionate Friends began as a response to the death of children from a flu epidemic. In 2018, some 37 years later, families are losing children through many causes – cancer, road accidents, drug overdoses and increasingly from suicide.

TCF is presently involved in a project to connect with the professions involved in family bereavement to make them aware of the ongoing peer support that The Compassionate Friends can offer.

In a recent TCF magazine, one bereaved mother expressed the devastating, lifelong pain of losing a child in these words:

“When we talk about our lives we talk about before and after – it is a pivotal point in our lives, like a whole new life started after our loss. We are not the same people we were before – the whole world is different – finding out how to exist when you are different in a different world is a really tough journey.”

The Compassionate Friends is dedicated to walking alongside bereaved families on this tough journey.

Find out more about [The Compassionate Friends NSW at the WayAhead Directory](#).

By Helen Murcutt