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POSITION STATEMENT ON BEHALF OF FAMILIES / WHANĀU

Who are we?

The mission of Supporting Families in Mental Illness (SFNZ), formerly known as the Schizophrenia Fellowship is to provide the best possible education, advocacy and support for family / whanāu of people experiencing a major mental illness. We have community based independent SFNZ societies across New Zealand and a National Council of elected volunteers. We believe that families and whanāu can play a key role in the recovery process. We use the terms 'family' and 'whanāu' to describe anyone who cares for or supports a person experiencing a major mental illness.

Skilled, professional Field Workers form the backbone of our service providing a range of practical interventions at times of crisis right through to recovery¹. They help ensure the voice of family / whanāu is heard when clinical decisions are made. The case studies and testimonials attached to the end of this document demonstrate how this is done.

¹ Recovery is a process, beginning with diagnosis and eventually moving into successful management of your illness. Successful recovery involves learning about your illness and the treatments available, empowering yourself through the support of peers and family members, and finally moving to a point where you take action to manage your own illness by helping others.
http://www.nami.org/template.cfm?section=About_Recovery

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Who do we serve and what do they want?

SFNZ family / whanāu members provide substantial unpaid care to loved ones facing major mental illness. Their experiences vary but there are general issues that they confront. First and foremost it is the reality for families and whanāu that treatment in the health system cannot succeed unless health professionals engage fully, openly and honestly with family carers. This is the case for all aspects of the system, from entry into the mental health sector (including general practice, diagnosis, and admission), in-patient experience, discharge, follow-up, recovery, relapse and readmission.

Family members experience the effects, impacts, changes and interactions of their loved one experiencing major mental illness. They are therefore able to identify material issues of concern that may trigger, aggravate or moderate the effects of the illness. These may be subtle, hidden by their loved one, minimised by casual observers or disregarded by health professionals.

We promote the Code of Family Rights²; a culturally appropriate, family centred approach to treatment by health professionals who understand, respect and take families seriously when they express concerns about changes in a family member's behaviour and provide information to families on the illness, diagnosis, treatment and side effects.

Families expect to be given the opportunity to confidentially provide information on the history of their family member, to be included in planning, treatment, reviews and to be consulted on discharge plans. They expect to be able to seek other opinions regarding diagnosis and to have access to complaint and redress mechanisms. They expect to have the names and contact details of the care team, to be provided help for problems caused or exacerbated by caring for their family member, including respite 'time out' and to have a rapid response in an emergency.

² <http://www.supportingfamiliesnz.org.nz/SFMI%20code%20of%20family%20rights%20brochure.pdf>

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The Royal Australian and New Zealand College of Psychiatrists

SFNZ notes the extensive work undertaken by the Royal Australian and New Zealand College of Psychiatrists and commends their position statement Supporting Carers in the Mental Health System, number 76, December 2012. It is, in our view, important that the recommendations in that paper be seriously considered in the implementation of mental health services³.

In 2006, 420,000 New Zealanders identified themselves as carers. Many carers are spouses, parents, family / whānau members, children or friends and many face difficulties with their own health, employment and finances. The College recommended action to ensure that carers receive appropriate support and services to assist them in their role (early identification of carers so they are visible, the preparation of Advance Directives for family members with mental illness to assist medical staff, alert carers and provide prompt treatment when required, and Carer Nomination forms⁴ to identify who, and to what extent, information-sharing is permitted).

The US National Alliance on Mental Illness (NAMI) position on Psychiatric Advance Directives (PADs) is that there are many potential benefits to PADs: (Allowing consumers to make their own health care decisions; Enhancing communication between consumers, their family and their treatment provider; Allowing for early intervention; Reducing court proceedings regarding involuntary treatment). The use of advance directives for psychiatric decision making is relatively new, and there are unresolved questions about the use of PADs. Ongoing research projects and pending court decisions should provide more information. In the meantime, PADs should be considered as a way to empower consumers to take a more active role in their treatment, and as a way to avoid conflicts over treatment and medication issues.

The importance of carers is recognised in the NSW Mental Health Act 2007, and specifically their need to access information about the person living with a mental illness (the consumer) so as to provide care and support, whilst at the same time giving the consumer the right to control who will be accessing this information. A consumer can nominate their 'primary carer', i.e. the person the mental health facility will contact, share information with and involve in the consumer's treatment and discharge planning, if the consumer does not have a guardian or is over 18 years of age. Consumers are also able to exclude a person or persons who they do not wish to receive information about them or their treatment.

A range of notifications and other information is to be provided to nominated primary carers including information about magistrate inquiries, medication, and discharge planning. The nomination stays in force for a 12 month period if there is no change requested by the consumer. The consumer can change this nomination or reverse it at any time. To facilitate the nomination of primary carers under the Mental

³ [http://www.ranzcp.org/Files/ranzcp-attachments/Temporary/76-Support-for-carers-in-the-mental-health-sys-\(1\).aspx](http://www.ranzcp.org/Files/ranzcp-attachments/Temporary/76-Support-for-carers-in-the-mental-health-sys-(1).aspx)

⁴Primary Carer Nomination Forms are provided for in legislation in many jurisdictions – for example see NSW https://www.slhd.nsw.gov.au/MHealth/cms/files/Carer_Info/Nomination_of_Primary_Carer_form_MHA_2007.pdf

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Health Act, NSW Health has developed a 'Nomination of Primary Carer Form' for consumers to fill out nominating their preferred carer.

The report also recommended improved mental health training for health professionals, especially frontline, a national mental health literacy campaign (to promote recognition of early signs of illness, the need to seek help and the value of early action). Health professionals are encouraged to develop better understanding of the role of carers in assisting the treatment and recovery of consumers and in mediation when conflict and tension arises between consumers and carers, along with support and advice for carers so that they maintain their own health⁵.

The Privacy Act

SFNZ believes that service providers across the Mental Health sector must not use the Privacy Act to stop them from seeking the views of family / whanāu members on treatment options, even if the person under treatment does not wish the service providers to pass on information to families / whanāu. We are of the strong view that families / whanāu are the experts; they know all aspects of the history and can best judge whether their loved ones are at risk of harm to themselves or others, are getting better or worse and what works or does not work in treating their illness.

SFNZ believes that the Code of Family Rights needs to be given statutory authority. This, in part will address the uncertainty which leads to denial of essential information between clinicians and families. For example, the principles underlying the *The Caregiver Recognition Act*⁶ in Manitoba provide a base for legislation:

- The relationship between caregivers and the persons for whom they care should be recognized and respected;
- The valuable social and economic contribution that caregivers make to society should be recognized and supported;
- Caregivers should be acknowledged as individuals with their own needs within and beyond the caring role;
- Caregivers should be supported to enjoy optimum health and social well-being and to participate in family, social and community life;

⁵ For an example of a dedicated carer model see – <http://www.carersnsw.org.au/page/640/carers-of-people-with-a-mental-illness>

⁶ <https://web2.gov.mb.ca/bills/39-5/b042e.php>

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- Caregivers should be considered as important contributors with other care providers in the provision of care, support or assistance, acknowledging the unique knowledge and experience of caregivers;
- Caregivers should be treated with dignity and respect;
- Caregivers should be supported to achieve greater economic well-being and sustainability and, where appropriate, should have opportunities to participate in employment and education; and
- Support for caregivers should be timely, responsive, appropriate and accessible.

The Senate Committee examining the need for this legislation defined the problem in the following terms:

“First, they (caregivers) must suffer with their loved ones through their daily hardships and use their limited personal resources to try to alleviate them. Second, they must contend with a mental health system that often excludes them from involvement in the information-gathering and decision-making processes... while simultaneously leaving them to serve as the fail-safe mechanism to provide unlimited, unpaid care, filling in the cracks that open when any part of the so-called system fails.”⁷

Inadequate Housing – what are we doing about this?

A lack of affordable, warm accommodation is perhaps the most significant issue facing family members affected by major mental illness. The situation has been described as appalling in many locations. SFNZ is committed to helping to address this issue, through a variety of mechanisms. We have commissioned research⁸ into barriers to access to housing for people with major mental illness⁹. Easy Access housing is a service provided in Wellington¹⁰. The SFNZ Housing Trust has provided¹⁰ substantial funding for dedicated housing in partnership with *Lifewise*¹¹ in Rotorua and *ComCare*¹² in Christchurch. The trust would welcome bequests with an assurance that funds will go to dedicated housing for people with a mental illness administered by professional and credible partners.

Children of parents with mental illness and/or addiction

Children of parents with a mental illness and/or addiction (COPMIA) require particular attention to ensure that these vulnerable people are visible, supported and given assistance

⁷ See our submission regarding the NZ Carers' Strategy at

http://www.supportingfamilies.org.nz/Libraries/Documents/SFNZ_submission_CARERS_STRATEGY_2013_docx.sflb.ashx

⁸ Grateful thanks to David Pickens, Public Policy Consultant and Contractor

⁹ A discussion document on accommodating people with serious mental illness - Can we do better? With assistance from Social Service Providers Aotearoa - <http://www.sspa.org.nz/> Have your say on this at <http://www.supportingfamilies.org.nz>

¹⁰ <http://atareira.org.nz/services/easy-access-housing-service/>

¹¹ <http://www.lifewise.org.nz/about-lifewise/our-services/mental-health-and-addiction-services>

¹² <http://mherc.org.nz/directory/accommodation-services>

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to cope and given assistance to develop resilience and to have access to other young people facing similar challenges and to adult mentors. SFNZ has made a significant investment in training its Field Workers and developing COPMIA interventions that make a real difference to the lives of children and their families¹³.

These interventions focus on positive themes – the child is not alone, they didn't cause the illness - it's not up to them to make them better - mental illness is just like a physical illness - anyone can have one - it's OK to ask questions and to talk to someone they trust about how they feel - don't push it aside - they do not need to be ashamed or embarrassed - it's OK to be angry, frustrated or upset – it's not selfish to take time out to do something they enjoy and the child has a right to feel safe.

Older people

For many older people, their quality of life is linked to their health, family and social networks, home and independence. SFNZ promotes mental health services for older people that proactively involve family/whanāu and friends to reduce social isolation and help them to manage their own condition/wellness. Many SFNZ family members are ageing and express concern about the fate of their family members with serious and enduring mental illness under their care should they die or be hospitalised. SFNZ expects particular focus to be given by health professionals to older people who are the prime carers of a family/whanāu member with a mental illness.

People with high needs and complex mental health challenges

A particular difficulty in maintaining focus and commitment in the health sector is the treatment and care of people with high needs and complex mental health challenges. Often, families as carers experience a reluctance from professionals to engage in a meaningful manner in treatment for loved ones with addictions; too often a judgement is made that the alcohol or other addiction is a barrier to treatment and therefore decisions are taken to

¹³ If you would like to know more or contribute your experience go to <http://supportingfamilies.netfinity.co.nz/resources/forums/mental-health/family-talk/copmia-children-of-parents-with-mental-illness-addictions.aspx>

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avoid, terminate or delay treatment. The burden of care relinquished by the health professionals in these circumstances inevitably then falls squarely on to family carers.

The challenges faced by family, whanāu and carers are significantly affected by new or different toxic substances - insidious and highly addictive generators of psychosis in vulnerable people with a mental illness. Perceived abandonment by health professionals of these vulnerable and sometimes irrational or risk-taking individuals can lead to impulsive actions including self-harm, or harm to others. Desperation often exacerbates an already tense situation and may lead to irreversible health problems or even preventable suicide.

Prevention first - unwell people who offend

SFNZ is concerned that people with mental illness who exhibit anti-social behaviour or commit minor crimes are often unnecessarily placed before the criminal courts. Police have well established diversion schemes in place with the aim being to treat offending as a symptom of an underlying problem – the focus being to address the cause. In the case of mental illness, the need for diagnosis, treatment and support is sometimes overlooked in these cases. Police also have well established alternative resolution schemes and restorative justice approaches can also be used to avoid the unnecessary criminalisation of people who are unwell. SNFZ encourages people in the criminal justice system to adopt a prevention first approach – by providing the opportunity for health interventions first.

SFNZ is concerned that despite positive outcomes a Watch-house Nurse (WHN) initiative trialled in several Police stations has not been continued or implemented elsewhere. This was operating at the Christchurch Central, Counties Manukau and Rotorua Police station watch-houses. The initiative placed appropriately qualified nurses within the watch-houses to assist the Police to better manage the risks of those in their custody who had mental health, alcohol or other drug (AOD) problems. Where appropriate, the nurses also made referrals for detainees to treatment providers.

The WHNs undertook over 6,000 assessments with detainees in Police custody to assist in clinical management. There was strong evidence, especially from feedback from Police

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custodial staff, that the WHNs were reducing the risks of harm to detainees and staff. Feedback from key stakeholders and analyses of the WHN databases provides strong evidence that the WHNs are liaising with other service providers and referring detainees. Feedback from Police custodial staff and the WHNs themselves provides evidence of the on-going education to Police particularly on an informal basis¹⁴.

Family violence – the risks posed by people with mental illness

SFNZ notes that mental illness is often cited in cases of family violence; however it is the least likely factor to increase the risk of lethality. The presence of the following factors significantly increase the risk of lethality—in order of importance—threats with a weapon, threats to kill, attempts to choke or strangle, forced sex, presence of a gun, escalating severity and/or frequency of violence over time, extreme jealousy/control, drug and/or alcohol abuse, and abuse during pregnancy. Other factors indicated for lethality include the perpetrator stalking the victim, the victim having a child in the home who is not the biological child of the perpetrator, the victim leaving or being estranged from the perpetrator, and last of all the perpetrator having a mental illness¹⁵.

People with mental illness in our prisons

SFNZ is concerned that New Zealand does not comply with the *United Nations Minimum Standard Rules for the Treatment of Prisoners*. Imprisonment is the loss of freedom, not a punishment of maltreatment or poor health¹⁶. Prison healthcare is reactive rather than proactive and mental healthcare is inadequate or unsuitable. Issues such as addiction and mental health conditions continue to motivate the same offending behaviour. Prisoners facing these issues are denied appropriate support while incarcerated and do not receive continuity of care upon release, increasing the chance of recidivism.

¹⁴ Evaluation of the Mental Health/Alcohol and Other Drug Watch-house Nurse Pilot Initiative, NZ Police (2010)

¹⁵ Family Violence Risk Assessment Review of International Research, NZ Police (2011)

¹⁶ Ombudsman's report on mental health services available to prisoners (2011)

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The prison suicide rate is eleven times higher than that of the general public, which can be attributed to the high number of prisoners suffering from mental health disorders which can go mistreated or undiagnosed¹⁷. Prison is a distressing social environment unlike what most New Zealanders experience: a culture marked by intimidation, assault and sexual violence. Living in this environment would undoubtedly promote the development of mental illness which would go untreated when released from custody, increasing the likelihood of a difficult and complicated reintegration and possible recidivism¹⁸.

The distress of suicide

Levels of suicide in our communities are higher than the road toll and each event causes widespread distress. SFNZ supports families / whanāu in dealing with the distress of suicide. Field workers therefore provide their expertise, knowledge and understanding in working with a wide range of individuals and organisations that aim to prevent suicide. SFNZ applauds the efforts in communities that are being taken to deal with the symptoms and underlying causes of suicide.

We want your ideas, assistance and support

SFNZ encourages interested parties, family and whanāu, health professionals and like-minded organisations to contact us to ensure our services remain relevant and valuable. Our AGM and Conference in Wellington this October will focus on the need to speak openly about self-harm and suicide. If you are able to attend or assist with sponsorship for this important event, please let us know.

John van der Heyden

President

National Council

¹⁷ <http://justspeak.org.nz/mental-health-treatment-and-services-in-nz-prisons-are-inadequate/>

¹⁸ Auditor-General's report, referred to in the above article

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Some case studies and testimonials

We helped a young mother with very high needs five year old with 1:1 support at school. Mum was unaware of what help was available. We organised a physically demanding contact sport, a free business management course so Mum could work from home. The child's behaviour improved with the increase in physical activity and with clinical help their lives are back on track.

A family had difficulty advocating for their daughter/sister to have more specialised care than the acute ward. With alcohol, addiction and self-harm difficulties the risk of suicide was high. We facilitated a meeting with clinicians the led to rehabilitation.

"I can't tell you how much our family has appreciated your support over the last few months. At times it had felt as though we were fighting a losing battle, so to have you on board was both a relief and a confidence boost. It helped us stay strong."

We helped parents who were supporting their son to recover from a psychotic episode after using synthetic cannabis. We advocated on their behalf with Community Mental Health Services. He is now attending programmes at a local mental health NGO to up skill before applying for part-time work. The parents have attended our Family Support Group and continue to receive contact and support from me as required. The son has been free of drugs and alcohol for six months.

A grandmother caring for her granddaughter because her mother was too unwell to care for her, found the strain very demanding. The child was socially isolated, lacked confidence and a victim of bullying. The relationship was at risk. We introduced the child to another child facing similar issues. They formed an ongoing friendship reducing isolation and building confidence understanding mental illness. Each now has their own safety plans identifying family and community support. This helped reduce their internalised stigma. A change and resiliency programme empowered them resulting in positive outcomes.

A lot of families are isolated and very private and our face to face home support takes away barriers that families face. They feel important, supported, and well-resourced and the process takes away their anxieties, and gives them a feeling of hope. Families have expressed how important it was to receive or to be educated around a diagnosis. After the initial shock we position them for self-care and ask questions that make them stop and think about themselves when they would not usually do so.

"My husband has been suffering from mental illness and his clinician introduced me to SF because I need support. The Asian Family Fieldworker understands my culture and background. When I feel exhausted and sad, she helped without me losing face. If he has a bad temper, depression or anxiety that affects me. She hears my story and gives me some suggestions and strategies to give our family great help. Her work is very important for me as I have my confidence back and feel comfortable to look after my kids and my husband again and be part of our community."

A family member has a wife who had been treated by mental health services for quite some time. He never talked or wanted to talk with anyone regarding his wife's' condition. He was even reluctant at first to talk with SF. Since then he has found much support through our service, talking about the grief he had felt when his wife first became unwell and all the other emotions which he said was a huge relief for him to let out. He thought he was the only one experiencing some of the challenges he faced, but since then he has been able to meet with other family members through the support group he has been able to unburden a load which he had carried himself for a long time.

Our Family Support worker supported an elderly mother and her middle aged son with a long term mental illness who lives with his mother. She was able to listen really well to the son and not react to his angry and aggressive manner. He revealed that he suffered very badly from anxiety and was constantly in considerable distress but had not revealed this to his doctor or any mental health staff.

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He is a difficult and unpleasant person to deal with who had been "written off" by local mental health support workers. This was disclosed and treated and the process of recovery is in place.

Parents and partners doing the Family Connections Programme report gaining much greater understanding of their family member with BPD and increased harmony and communication in the home. This has led to less Crisis team/Police call outs and hospital admissions. Family members with mental illness were encouraged to accept treatment and family members are less stressed, depressed and anxious. Recovery plans are in place and the process has been a safety valve for the families.

One family had been dealing with their daughter's mental illness for over 10 years but had never been given any information regarding her schizoid-affective disorder, having information about the illness gave the parents more confidence to ask their daughter's keyworker questions about how they could best support her. The daughter is now living independently with support.

One solo mum of a young child shares a home with her mother (co-owners) who has bi-polar, and meets regularly with our support worker to keep a 'normal' perspective of life as her mother will not take her medication regularly. Phone contact is a life-line for this young mother whose siblings don't want to be involved with their mother.

New Settler families struggle with their family members' mental illness because of the language barrier, some being willing to travel to SF seminars in their own language. One met with our support worker to discuss their son's current treatment plan. They see little improvement in his mental health and as he lives at home, and culturally he would not live independently, his mother becomes very exhausted emotionally and physically. They were encouraged to take up walking, which calmed them. Their situation has not changed, but their involvement in life and activities no longer centres entirely around their son with the psychotic illness.

"I wanted to thank your organisation for making it possible for me to access this amazing resource. I found the course invaluable in allowing me to learn about my depression and then to move me along to places where I could learn "tools" that, with practice and support, I can apply to improve my wellness. The group was so well facilitated, clear, empathetic, supportive, safe, encouraging and inspiring!"

We received a referral after police were involved with a daughter with a diagnosis of PTSD who became quite volatile at times. A carer had depression and a mood disorder and had not taken his medication for some time. We arranged a medication review. We persisted to get referrals despite ongoing trauma and domestic turmoil. We attended meeting with clinicians and a psychiatrist along with CYFS. The carer was given a change in medication that worked so well he realised he had "lost" so much of his life. The couple, who had been separated, are now back together with a support plan in place for their daughter.

A daughter contacted us as she was extremely concerned about her elderly parents. She believed her father was developing dementia and becoming too difficult for her mother to care for on her own. The daughter lived some distance away and was unable to assist her mother. She phoned local agencies looking for help but received none. She finally phoned us in desperation. We assured her that we could help as we hold a contract to work with the elderly persons. We offered our support and have successfully arranged Enduring Power of Attorney, an Advanced Care Plan, assessment to obtain respite care and home personal care, and a medication review. Her mother feels supported and able to continue to care for her husband.